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THE PAIN OF RHEUMATOID  
ARTHRITIS:  
THE DIFFERENT PERSPECTIVES  
OF PATIENT AND  
RHEUMATOLOGIST  
(Volume 1)

STELLA HOWDEN

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of the requirements for the degree of  
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## ABSTRACT

The chronic pain associated with rheumatoid arthritis (RA) is identified by patients as a priority for treatment and is said to shape their illness experience. However, review of the literature reveals that little is known about patients' perspectives on pain in RA, with even less being known about how rheumatologists, the clinical experts in patient care, perceive this phenomenon. Increasing knowledge and understanding of patients' and rheumatologists' perspectives on pain can be used to try to influence their action/inactions as well as helping to identify patients' specific concerns and unmet needs.

The aims of this study were:

- To describe patients' and rheumatologists' perspectives on the meaning of pain in RA;
- To explore how these pain meanings are constructed; and
- To consider the implications of these constructions for pain management.

This interpretive, qualitative study used semi-structured interviews to generate accounts related to respondents' perspectives on pain in RA. Purposive sampling was used to select a heterogeneous group of patients with RA (n=29) and rheumatologists (n=16). Thematic analysis was used inductively to generate findings using a cumulative, constant comparative technique (Strauss and Corbin, 1998).

Both patients and rheumatologists presented multiple pain meanings but generally viewed pain as an expected symptom of the disease, both being resigned to the belief that most patients would have some degree of daily pain. Additionally, both groups considered the pain experience to have a pervasive, negative impact on life, potentially threatening the patient's concept of 'self'. In contrast, patients' and rheumatologists' pain meanings regarding *clinical* topics were not similar. Patients' views of medical responsibility were narrowly defined, rooted in western biomedical conceptions of pain and were influenced by experiences of clinical interactions.

Accordingly, patients viewed the rheumatologist to be responsible only for 'legitimate' pain i.e. pain associated with the body and disease processes. Rheumatologists, on the other hand, presented a more comprehensive understanding of pain by incorporating psychological and social theories along with an associated 'ideal' model of care (reflecting a biopsychosocial approach). Consequently, they identified eclectic roles/responsibilities for themselves in patient management. However, rheumatologists viewed this 'ideal' as difficult to attain in the

context of their experiences of clinical work where multiple constraints were perceived to exist, such as difficulties in deciphering pain, the perception of limited resources (e.g. time) and organisational barriers. In light of this, their role was often reduced to focusing simply on disease management, thus displacing the 'ideals' of patient-centred care and perpetuating the dominant biomedical discourse of pain in the clinical context.

This thesis adds to the body of knowledge about patients' perspectives on pain when they live with a chronically painful condition and patient barriers to reporting pain. New findings are presented regarding the medical experts' conceptions of pain; in particular, those related to complex clinical work. The findings also identify areas of unmet need regarding patients' knowledge of pain, pain management and of the roles and responsibilities of healthcare professionals. Suggestions are made for further work in the areas of investigating patient barriers to reporting pain; exploring patient perspectives on self-management and using alternative research methods to complement and develop the findings from this study.

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# 1 CHAPTER ONE - INTRODUCTION

Pain is a complex phenomenon, something private and subjective but at the same time ubiquitous; a part of human experience, with people in society sharing a common understanding of it, how it might feel, what it signifies and how it comes about. This study explores what patients with the chronically painful condition, rheumatoid arthritis (RA), and medical specialists in RA management (rheumatologists) think about pain in RA and how they make sense of it. Patient and rheumatologist pain perspectives are examined for similarities and differences, and the consequent implications for pain management discussed.

## 1.1 THE NATURE OF MEANINGS RELATED TO PAIN

The experience of pain always forces the individual to find meaning in it (Aldrich and Eccleston, 2000; Kleinman, 1992) however, these meanings are complex and changeable. Although there is a limited number of ways of making sense of any phenomenon within society (Stenner and Eccleston, 1994), meanings of pain are a product of multiple influences; culture, society, cognition, emotion and bodily experiences, these variables also being, time, context and situation dependent (Cassell, 1982; Locker, 1981). In this way some 'ways of knowing' about pain are likely to be shared whilst others may be unique to the individual, patient or doctor.

Firstly, knowledge of patients' and doctors' meanings of pain is relevant to patient care for several reasons. Exploring patients' accounts of pain; their explanations, understandings and experiences reveal something of the insiders' perspective of how pain impacts upon life, thus helping to identify their unmet needs, specific concerns or fears related to pain, any or all of which have to be addressed. Knowing what factors or processes shape individuals' perspectives on pain enables appropriate support and information to be provided in the context of effective pain management.

Secondly, qualitative study of both patients' and rheumatologists' perspectives on pain allows development of understanding of their respective interpretive frameworks, the filters through which they ascribe the significance of events or phenomena which shape their actions and interactions (Berger and Luckman, 1967; Brown, 1985). The comparison of these two potentially different but overlapping conceptual worlds allows discussion of their separate functions and the type of influences they may bring to bear on one another. Both patients and doctors

have complex and well developed 'ways of knowing' about phenomena, like pain and illness; however, these do not always coincide (Eccleston et al, 1997; Stainton Rogers, 1991) and this has implications for the effectiveness of communication and patient-doctor relations (May et al, 2000; Peters et al, 1998; Tuckett et al, 1985b).

Exploration of patients' and rheumatologists' conceptions of pain in RA; in particular, in relation to clinical issues can therefore inform practice (May et al, 2004; Popay et al, 1998).

## **1.2 RHEUMATOID ARTHRITIS AND PATIENTS' PAIN EXPERIENCE**

Rheumatoid arthritis is the most common form of inflammatory joint disease affecting around 387, 000 people in the UK (Arthritis Research Campaign, 2002), with an estimated prevalence in the UK of 1.16% in women and 0.44% in men (Symmons et al, 2002). The burden of RA is likely to heighten with an ageing population and improved management of co-morbidities of those already diagnosed with RA (March and Lapsley, 2001). This systemic condition remains incurable and affects individuals in varying degrees. Those attending rheumatology clinics generally present with significant disease progression and functional decline (Conaghan et al, 1999). Pain is a key feature of RA commonly presenting in multiple small joints of the body with variable intensity (Rice and Pisetsky, 1999). Patients identify pain as one of the most important consequences of the disease (Katz, 1998; Melanson and Downe-Wambolt, 2003) and rate it as a priority for treatment (Heiberg and Kvien, 2002; Minnock et al, 2003). Increasing pain in RA is also associated with decreasing quality of life (Lambert, 1985; van Lankveld et al, 1994).

Current pain theory suggests that the pain experience is generated from the integration of multiple mechanisms, the product of a complex neurobiology operating in tandem with changing meanings (Melzack, 1999). The role of the individual's interpretation of painful sensations is vital in shaping perceptions of pain sensations, affective and behavioural responses (Turk and Okifuji, 1999). On one hand, evaluation of pain-related literature in RA within clinical, biological, psychological, social and anthropological domains, highlight the dominance of empirical orientated research, focused upon determining the relationship between measurable dimensions of pain (e.g. pain intensity) and disease indicators or demographic variables. Whilst, on the other hand, patients' pain meanings and the cultural and social factors considered to be the foundation of these, shaping pain expression and its treatment (Rey, 1993) are sidelined. Studies of chronic pain in sociological and anthropological fields have

been criticised for failing to address relevant clinical issues (Chard et al, 1997; Williams, 1999), a point well articulated by Kleinman (1980, p xiii):

..these studies often are so remote from or irrelevant to the chief interests of a clinician: the exigent and difficult reality of illness as a human experience and the core relationships and tasks of clinical care, even research by health scientists, has had little or nothing to say about these clinical issues.

Qualitative studies exploring patients' experiences of RA generally present the consequences of life with RA, with limited detail regarding conceptions of pain and pain specific accounts (Bath et al, 1999; Brown and Williams, 1995; Ryan, 1996). Those with most reference to experiences and explanations of pain (Bury, 1988; Locker, 1983) collected data in the late 70s and early 80s and are not now directly comparable to the current situation as treatments and outcomes in RA have changed significantly (Conaghan et al, 1999; Fries, 2000). This contrasts to the relatively extensive exploration of the experiences and pain conceptions of those with chronic pain of medically undefined origin (e.g. low back pain) i.e. those patients perceived to be 'problematic' or medically challenging cases. Metasynthesis of key findings from these studies (in Chapter Four) finds consistency in highlighting issues of legitimacy and the threat of pain to self, themes not developed in the RA literature. This further strengthens the argument that current understanding of patients' pain perspectives in RA is, at best, limited.

### **1.3 MEDICAL EXPERTS' VIEWS OF PAIN IN RHEUMATOID ARTHRITIS**

Rheumatologists identify the reduction of painful symptoms and associated sequelae (e.g. impaired function) as a significant role for them, either directly delivering care or via co-ordinating other people and services (Scott et al, 1998). Studies of doctors' perspectives on chronic pain (or pain in general) are limited, commonly reliant upon survey or questionnaire methods, conducted in the USA and predominately from the field of cancer pain research (Rich, 2003). Such studies fail to reveal the complexity and variability of medical experts' understanding of pain (reviewed in Chapter Five). Review and critique of clinical articles and inferences from rheumatological clinical texts suggests that dualistic notions of pain persist in rheumatology, maintaining the distinction between organic and psychological dimensions of pain. This suggests that continued simplification of locating the 'source' of pain within distinct categories of body or mind persists and the priority of the notion of 'disease' over the description of the individual's experience and perspective remains, as was described over ten years ago (Bendelow and Williams, 1995; Good, 1992).

Aside from the lack of knowledge about rheumatologists' views on pain, overall it is recognised that, clinically, pain is poorly assessed (Rutledge and Donaldson, 1998) and under-treated (Rich, 2003) with suggestions that patients and doctors do not communicate effectively regarding the importance of pain and its alleviation (Kwoh et al, 1992). The phenomenon of pain is unseen, resistant to words and measurement (Scarry, 1985).

Theoretically, the patient's verbal report is the gold standard of pain assessment (Rutledge and Donaldson, 1998) but this is dependant upon the patient communicating their pain and the doctor understanding and valuing this information together with the other clinical information gathered. It has been suggested that effective patient-doctor communication in RA is 'hampered' by the lack of understanding by health professionals of how patients understand their symptoms (Griffith and Carr, 2001, p85). This further emphasises the need for inquiry into medical knowledge in relation to its 'used form' in the clinical context, where patient and doctor meet (Dingwall, 1992, p167).

## **1.4 PATIENT CARE IN RHEUMATOID ARTHRITIS**

Medical care is interwoven with the lives of those with RA. More than 75% of patients are referred to hospital specialists (rheumatologists) and are reviewed at hospital clinics from diagnosis onwards (Gray and Muirie, 2002; Harrison and Symmons, 2000). The model of care used by most services in Scotland is 'shared care' where primary and secondary care services work together; the GP and hospital based specialist (along with the multidisciplinary team - where available) are all involved in managing patients with RA (Gray and Muirie, 2002).

The 'chronic disease management model' (Lewis and Dixon, 2004) is promoted as relevant for care in RA (Gray and Muirie, 2002) in preference to a biomedical, disease focused approach which tends to fail rheumatological patients (Callahan and Pincus, 1997; Foster et al, 2003). This patient-centred approach to management includes adopting a biopsychosocial perspective to illness and considering the personal meanings of illness for patients (Mead and Bower, 2000). Focus upon patients' experiences and concerns result in greater patient satisfaction (Lewin et al, 2004) in contrast to situations where patient-professional perspectives are discordant and communication fails (Donovan and Blake, 2000; Tuckett et al, 1985b). Exploration of patients' pain experiences and wider meanings of pain in RA provides opportunity to identify patient needs whilst providing clinicians with deeper understanding of the patient's experience and ways of thinking about and describing pain. Knowledge of rheumatologists' conceptions of pain provides information relevant to understanding the complexity of clinical

work in relation to the patient with chronic pain. It also enables comparison of patient-doctor interpretive frameworks and discussion of the implications for communication and pain management in general.

## 1.5 THEORETICAL STUDY PERSPECTIVES

To explore patients' and rheumatologists' meanings of pain in RA, a qualitative interpretive study design was adopted, focussing on participants' linguistically available accounts related to pain and RA. The term 'account' refers to the story or narrative presented by respondents and 'meaning' is defined in its widest sense (i.e. the perspective of the individual) to promote the generation of a diversity and profusion of stories, ideas and explanations offered by participants. 'Meaning' in this context is that which the individual creates and attributes to the course of their life or experiences, rather than the, 'ultimate' meaning of life, related to perspectives on life, death and the unknown (Conrad, 1990, p 1261). [In this way, subjectivity, lay and expert views were privileged as sources of expertise and understanding in relation to pain, illness and disease (Popay et al, 1998).]

Within any culture, at any given time, there are multiple explanations that can contribute to how pain is understood (Stenner and Eccleston, 1994). The influence of society and culture on the construction of meanings of pain is one of the key sensitivities integrated within the study alongside experiential, contextual and historical factors that act to shape and elicit re-negotiations of meanings as individuals interact with each other and their world. This view is consistent with the ontology of constructionism, where meaning is not discovered but constructed, where knowledge is contingent upon human practices and is constructed through interaction between people and their world at any given time (Crotty, 1998). There is therefore no 'true' interpretation but the strength or 'validity' of an interpretation is dependent upon its apparent usefulness (Patton, 1990).

Within the study the researcher's influence is acknowledged and reflected upon i.e. how the researcher affects the findings, accepting that the findings will represent the researcher's construction of what they and respondent co-created at interview. The focus was on developing a strategy and framework that present to the researcher and reader a means to assess the inherent subjectivity of the work and the degree to which findings were grounded within participants' accounts. In this way it is accepted that bias is not eliminated through the researcher's commitment to be reflexive, it is accounted for rather than ignored (Malterud, 2001b). Inspiration is drawn from various disciplines, traditions of research and studies investigating pain and chronic illness e.g. social

constructionism, symbolic interactionism, interpretive phenomenology and medical anthropology. It is accepted that the pain phenomenon will always be greater than the sum of its parts (Carter, 1998, p86) and that the phenomenon itself will always escape the scrutiny of the researcher. However, the broad approach assumed here towards studying participants' perspectives on pain in RA holds a uniting interest for both parties which will inform clinical encounters and promote understanding of pain in RA.

## **1.6 RESEARCH QUESTION AND AIMS**

The primary research question is - What is the meaning of pain in rheumatoid arthritis from the perspective of both patients with the condition and of rheumatologists working with such patients? The main research aim was to explore the meanings of pain in rheumatoid arthritis from the perspective of patient and rheumatologist, where 'meaning' includes individuals' intention, cognition, affect, belief, expectation and evaluation; i.e. things that can be encompassed by the broad term "the participant's perspective" (Maxwell, 1992). To achieve this, sub-aims were developed:

1. To describe what meaning/s related to pain in RA are offered by the participants, through talk, which reflect how they perceive pain in RA (including talk about pain management, relations between pain and RA, experiences of pain, causes and consequences of pain, pain and analgesia, clinical pain assessment etc)
  - both personal/individualised and shared/common meanings of pain in RA are to be explored
2. To explore how these pain meanings, related to pain phenomena in RA, are constructed i.e. explore the meaning-making processes or influences that support representations of the pain phenomena in RA (these factors may be cultural, social, contextual and/or experiential factors)
  - providing explanation for the meanings generated and identified
3. To compare and contrast patients' and rheumatologists' conceptions of pain in RA and consider what purpose these may serve for each group
  - exploring for commonality and uniqueness



4. To discuss the implications of all of the above findings with regard to management of pain and its consequences in RA

- with particular emphasis being placed on issues of patient unmet need/support, patient-rheumatologist communication about pain and patient-centred care

## **1.7 OVERVIEW OF THE THESIS LAYOUT**

Chapter Two provides the background to RA and situates pain within the context of what is known about the disease and the associated illness. This stresses the importance of pain in shaping the illness experience and illustrates how knowledge of disease is integrated with illness as patients seek ways to make sense of illness.

In Chapter Three an evaluation of the contribution made by a variety of different approaches to studying pain in RA is presented and this informs the patient sampling strategy used. It also emphasises the key role personal meanings of pain play in shaping the pain experience and behaviours. Gaps are identified in the extant literature and these are used to illuminate the research aims.

Chapter Four is a metasynthesis of qualitative studies exploring patients' views on pain for those with non-cancer, chronic pain conditions (e.g. LBP). Key themes are identified highlighting multiple social and contextual pain issues that have not been addressed in RA. A critique of the dominant methodologies in this field exposes the weakness of some of this existing work and the lack of rigour in interpretive qualitative research exploring pain views within western societies.

Justification of the need to explore rheumatologists' views on pain in RA, in particular with regard to clinical or working pain knowledge, is presented in Chapter Five.

Chapter Six presents the relevance of knowledge about patients' and doctors' perceptions of pain by examining the key components of the patient-centred model of care for chronic illness. This model emphasises the importance of effective communication and focuses upon understanding the individual's perspective on illness. Also discussed are the contextual barriers to the implementation of this approach within current rheumatology service provision in secondary care.

Chapter Seven presents the research theory and methodological justification relevant to the study of meaning of pain within a constructionist framework. The argument for adopting a pragmatic, interpretive, qualitative inquiry is made.

Chapter Eight outlines the methods. The first section of the chapter describes the exploratory phase where key informant discussions were used to affirm the relevance of the research and shape research 'mini-questions'. These research 'mini-questions' were then used to pursue study aims on the basis that they were grounded in areas that were seen to be relevant to patients and rheumatologists. The second section details the study setting, how accounts were generated along with the systems used for ordering and analysing accounts leading to the generation of themes and explanations regarding the inter-relativity of themes.

Findings and discussion are presented together over the final three chapters. Key patient and rheumatologist themes and conclusions are presented separately in Chapters Nine and Ten respectively. In Chapter Eleven patient and doctor themes are compared and discussed with focus upon the relevance of findings to patient care.

The conclusions and main findings from the study are presented in Chapter Twelve along with recommendations for further research.

### **1.7.1 Terminology and the Writer's Voice**

The use of the term 'patient' in reference to individuals with RA is not intended to discredit the individual by suggesting they are defined by their illness but is used for clarity, brevity and in recognition of the fact that individuals with RA identify themselves as 'patients' in accounts of medical interactions. The rheumatologists did likewise.

The interpretive nature of this qualitative inquiry and the constructionist philosophies that underpin it are testament to my pivotal role in shaping and presenting the findings. Progressivist qualitative research advances the writer's intent to state his or her argument and location within the study in the first person 'I' (Holliday, 2002, p23). To maintain a sense of coherence and in keeping with health science dissertation genre as being the primary

means of discourse of the health professions for whom I write, I have decided to write the study in the third person and I highlight my key role in shaping the argument and research agenda in the following ways:

1. By incorporating reflexive notes derived from field notes, research diary and memos; and
2. Making a clear distinction between respondents' actual words and my interpretation of them throughout both the findings and discussion sections.

## **2 CHAPTER TWO - RHEUMATOID ARTHRITIS: THE DISEASE AND THE ILLNESS**

### **2.1 INTRODUCTION**

Background to the study is presented by outlining the main areas of medical knowledge about RA, the disease, followed by an overview of patients' perspectives on RA i.e. the illness experience. The basis of medical knowledge about RA is relevant to the study as it situates pain within wider issues in RA presentation and management, and represents the dominant framework for rheumatologists' understanding of RA and pain (discussed further in Chapter Five). Review of patients' experiences of illness and identification of key themes within the literature situates the phenomenon of pain within accounts of experiences of RA.

Disease refers to pathological or detrimental physiological processes within the body. This is commonly associated with being the concern of doctors and the focus of the biomedicine i.e. a science based medical theory used to study the workings of the body. In contrast, illness represents the social and psychological consequences of living with disease, the personal experience of the condition and the meaning it holds for the individual (Nettleton and Gustafsson, 2002). Although the above mentioned disparate theoretical perspectives suggest an independent existence (Radley, 1994), these different ways of knowing about RA are drawn together in the final section of this chapter addressing patients' efforts to find meaning in illness. Patients' accounts of illness integrate medical theory and knowledge of disease with biographical detail, blurring the distinction between disease and illness constructs, suggesting that a similar process is also likely to be inherent in pain accounts.

### **2.2 RHEUMATOID ARTHRITIS: THE DISEASE**

#### **2.2.1 Defining RA**

Rheumatoid arthritis is an inflammatory polyarthritis, a chronic, systemic, autoimmune condition whose course is both unpredictable and variable. There is no exact definition of rheumatoid arthritis although there are recognised criteria used to identify it clinically; a mixture of signs and symptoms primarily relating to the articular manifestations of the condition (see Table 2.2.1 for the RA classification criteria).

**Table 2.2.1 American Rheumatism Association 1987 Revised Criteria for the Classification of RA (adapted from Arnett et al, 1988)**

---

Signs and Symptoms \*

---

1. Morning stiffness	Duration > 1 hour
2. Arthritis of 3 or more joint areas	Soft tissue swelling or effusion
3. Arthritis of hand joints	
4. Symmetrical arthritis	At least one area
5. Rheumatoid nodules	As observed by a physician
6. Serum rheumatoid factor	
7. Radiographic changes	As seen on films of wrists and hands

\*Four of the seven criteria listed must be identified for a diagnosis of RA.

---

Rheumatoid factor (RF) is a type of antibody found in approximately 60% of patients with RA and is the test most closely associated with being diagnostic (Conaghan et al, 1999). A positive RF test is however not conclusive as it can occur in people without the disease.

## 2.2.2 Epidemiology and the Economic Costs of RA

Rheumatoid arthritis is the most common form of inflammatory joint disease. Estimates for the United Kingdom report a prevalence of 1.16% in women and 0.44% in men (Symmons et al, 2002). There are around 387, 000 people with RA in the UK, approximately 0.8 percent of the population, with 12, 000 new cases each year (Arthritis Research Campaign, 2002). Rheumatoid arthritis can affect all ages although is most common in women aged 40-50 years. The incidence of RA is greatest for both men and women in the 65-74 years age group (Symmons et al, 2002). Women are affected more than men with a ratio of 2.5:1 (Lawrence et al, 1998).

Rheumatoid arthritis places a substantial financial strain upon the individual and society in general through days lost in work and through use of the healthcare services. Financial hardship is not uncommon in RA, the average family income potentially reduced by an average of 35% over the course of the illness (Wolfe and Hawley, 1998). The overall annual inclusive cost of RA in the UK is between £0.8 and £1.3 billion (calculated from direct medical costs, work disability costs and nursing home care costs (Scott et al, 1998)). The direct costs of treating

those with RA are estimated at two to three times the cost of age and gender matched individuals without RA (Lambert, 2001).

### **2.2.3 Aetiology and Pathology**

Although no single entity has been identified as the cause of RA it has been established that genetic susceptibility and environmental triggers play a part in its genesis, with infectious agents possibly implicated in triggering the disease (Ollier et al, 2001). Smoking and obesity have also been identified as risk factors for developing RA (Voigt et al, 1994). Disease pathogenesis in RA is complex, involving activation and infiltration of a variety of cell types; however, degrading enzymes within the synovial cells play a key role, culminating in joint inflammation, associated joint pain and stiffness, and ultimately irreversible joint damage (Maddison et al, 1993).

### **2.2.4 Clinical Presentation of RA and Prognosis**

There is great variability in the nature of onset of RA, severe symptoms may appear overnight or gradually present over a period of weeks or years and clinically patients present with mixed patterns and at different stages of their illness (Wollheim, 1993). Progressive disease, with periods of remissions and flares (disease exacerbation) associated with worsening physical impairment over time is a common course for those with clinic-diagnosed RA (Conaghan et al, 1999). Patients with RA typically present with symmetric, polyarticular pain especially within the small joints of the hand and feet, although larger joints e.g. shoulder can also be involved (Jayson, 1999). Extra-articular features of RA include rheumatoid nodules, vasculitis, peripheral neuropathy, lymph node enlargement, anaemia, pulmonary disease, and ocular manifestations (Green and Deodhar, 2001; Jayson, 1999).

Those with RA have an increased risk of mortality in comparison with the general population (Wolfe et al, 1994) and the disease is associated with numerous life threatening complications e.g. cardiovascular, gastrointestinal, and infectious diseases (Chehata et al, 2001; Jayson, 1999). Even with treatment to slow disease activity, over a period of 10 years patients present with functional decline and evidence of progressive joint deterioration (Gordon et al, 2001b; Wolfe and Hawley, 1998).

## **2.2.5 Medical Management of RA**

Rheumatoid arthritis can neither be cured nor prevented, however, medication and other treatments can reduce symptoms and slow underlying disease activity and progression of joint destruction (Fries, 2000). Early referral to a rheumatologist, the clinical specialist in RA management, is promoted for diagnosis and planning of treatment (Gray and Muirie, 2002).

Common goals for the treatment of RA include the points listed 1-6 below (Gray and Muirie, 2002; Scott et al, 1998; SIGN, 2000).

1. Control symptoms of pain and joint inflammation.
2. Reduce the risk of joint damage.
3. Reduce the risk of disability.
4. Maintain or improve quality of life and minimise the loss of function.
5. Manage extra-articular complications.
6. Involve and inform patients and carers in their care and treatment.

Pharmacology is the cornerstone of management in RA and current medical management involves the use of combinations of four classes of drugs: analgesics, non-steroidal anti-inflammatories (NSAIDs), disease modifying anti-rheumatic drugs (DMARDs) and corticosteroids (see Appendix 2.1 for details of the action, use and side effects of these medications). Disease modifying drugs are central to disease management as they target disease activity and are used early in treatment of RA and from that time onwards (Fries, 2000). These medications slow functional decline and reduce later disability (SIGN, 2000). However, despite receiving treatment for the underlying disease, many patients with RA continue to experience pain (Simon et al, 2002). Analgesics like Paracetamol and Co-Proxamol are used as an adjunct to relieve pain along with NSAIDs used to suppress pain by reducing anti-inflammatory activity and swelling. Opiates are often the last option considered for pain relief only used when other management strategies have failed (Simon et al, 2002).

## **2.2.6 The Multidisciplinary Team and Non-Pharmacological Therapies for Pain**

A multidisciplinary team approach to managing the patient with RA is promoted as best practice (Ahlmén et al, 1988; ARMA, 2004; Scott et al, 1998; SIGN, 2000; Vliet Vlieland et al, 1997). General practitioners,

rheumatologists, nurse specialists, physiotherapists, occupational therapists, psychologists, podiatrists, dietitians, social workers, pharmacists and surgeons can all be involved in patient care. The team can provide support, advice/information and reassurance to patients and family, practical help in dealing with activities of daily living and work as well as counselling and rehabilitation (Madigan and Fitzgerald, 1999; Stucki and Kroeling, 2000). Involving the patient in education, self-management programmes and support networks has also been shown to positively effect outcome (Barlow et al, 2000; Lorig and Holman 1993; Niedermann et al, 2004; Riemsma et al, 2003). A variety of non-pharmacological approaches for the management of pain in RA are possible e.g. patient education regarding self-management and coping skills training (ARMA, 2004; Robbins et al, 2001; Simon et al, 2002; SIGN, 2000). However, many of these are dependent upon resources and are acknowledged to be labour intensive (Evers et al, 1998; Superio-Cabuslay et al, 1996). Gaps between optimal treatment and routine practice in RA management exist. A particular shortfall is noted in areas affecting education and advice for patients, incomplete teams and lack of integration between primary and secondary care (Gray and Muirie, 2000; Scott et al, 1998). See Appendix 2.2 for details of non-pharmacological interventions for pain in RA.

### **2.2.7 Summary and Conclusions**

Rheumatoid arthritis is a chronically painful and disabling condition for which there is presently no cure and the causes of which are yet to be fully understood. The presentation of variable and fluctuating pain in multiple joints characterises the condition clinically and despite treatments to slow disease activity functional decline and on-going pain are common. The management of RA is multifaceted, the rheumatologist is often attempting to manage symptoms along with threats to mortality and complications of treatments within a predominately elderly patient group. Pharmacology is the cornerstone of treatments focused on using disease modifying drug therapies to slow both disease processes and the joint deterioration and thus improve long-term functional outcomes. Although ideal clinical management of RA involves multiple approaches and disciplines these are not always available and the opportunity to use the many non-pharmacological, psychosocial interventions to promote physical and psychological well being and reduce pain may not be realised in clinical practice.



## **2.3 RHEUMATOID ARTHRITIS: THE ILLNESS**

### **2.3.1 Introduction**

This section presents the lived experience of RA, the 'insider's' view (Conrad, 1987, p5) and incorporates patients' reflections of the impact of illness on their lives, including how they make sense of their experience. This represents a broader context within which to situate experiences and understanding of pain. Where possible, UK based studies are used to furnish this synopsis (e.g. Bath et al, 1999; Bury, 1982; Locker, 1983; Ryan, 1996). Evaluation of these studies emphasises the critical role that pain-experiences play in shaping illness in RA and thus exploring insiders' meanings in RA informs the thesis in these several ways:

- suggests the likely nature of pain meanings;
- proffering factors that may influence these meanings; and
- demonstrating compatible research approaches for exploring pain meanings.

Two main themes are identified from a review of illness experience studies: uncertainty, and searching for meanings in illness.

### **2.3.2 Uncertainty and the Problematic Nature of Pain**

Living with chronic illness often presents the individual with a range of social and emotional uncertainties along with physical impairment and restriction (Bury, 1988). All aspects of the individual's life as well as the life of those around them can be affected. Conrad (1987, p7-8) identified several types of 'uncertainty' deemed applicable to the illness experience in RA:

- Uncertainty regarding what early symptoms signify;
- Having the diagnosis but unsure of its significance;
- Uncertainty about how the disease/illness will progress;
- Uncertainty of symptomatic presentation day-to-day.

Several studies make reference to RA patients' pain experiences, however, the majority are dated and pain is not the focus of the study. It is reported that patients often ignore early symptoms of RA (e.g. pain or swelling) and delay seeking help where symptoms appear vague, transient or present gradually, as they fail to attribute this to being 'an illness' or signs of disease (Bury, 1988; Griffith and Carr, 2001; Sakalys, 1997). Painful sensations may

be normalised i.e. relating them to normal signs of ageing (Sakalys, 1997) or using common-sense explanations to make sense of what they experience e.g. injury (Brown and Williams, 1995; Donovan et al, 1989).

Diagnosis is greeted with a mixture of responses from patients, relief at finally having justification for their complaints and presentation of symptoms (Bury, 1982) and, for others, disbelief, anger or fear (Griffith and Carr, 2001; Sakalys, 1997). Furnished with an explanation for their symptoms patients face a new uncertainty about the future along with fears about what they may experience, concern about how they will cope (Bath et al, 1999; Ryan, 1996), or how the disease will progress (Archenholtz et al, 1999). The day-to-day unpredictability of the nature and duration of painful sensations is a recurrent theme in several studies. It is reported that being unable to predict how long, how intense or where pain will be experienced means that individuals are unable to plan activity (Brown and Williams, 1995; Locker, 1983; Wiener, 1975). However, these issues are not explored in depth and study aims vary e.g. exploring broad topics like suffering in RA (Dildy, 1996), experiences of RA (Brown and Williams, 1995; Ryan, 1996; Wiener, 1975; Williams and Wood, 1988), psychological and learning needs in RA (Bath et al, 1999; Neville et al, 1999) and how patients think about RA generally (DeVellis et al, 1997).

#### ***2.3.2.1 Disruption in everyday life threatening valued roles***

Pain, stiffness and fatigue all contribute to the difficulty that patients with RA encounter in carrying out tasks of daily living (Archenholtz et al, 1999; Dildy, 1996; Locker, 1983; Melanson and Downe-Wamboldt, 1995). Loss of, or impaired function results in problems with self-care, work, performing household tasks, mobility indoors and out (Bath et al, 1999; Locker, 1983; MacKinnon et al, 1994; Nemchand, 1997). Tasks that can be completed may take extra time but of most concern are circumstances where valued tasks or activities can no longer be performed (DeVellis et al, 1997; Griffith and Carr, 2001). Interference with tasks that have symbolic significance or personal value (e.g. a mother unable to lift her baby) may have profound effects upon the individual, creating a source of distress and disruption to the sense of identity (Brown and Williams, 1995; Dildy, 1996; Newman et al, 1996). Charmaz (1983) identifies the 'loss of self' as being a fundamental form of suffering in those with chronic illnesses (like RA) where the image of self (i.e. the individual's socially established organised attributes) is eroded without finding an equally valued replacement. Patients with RA regard their former (pre-illness) image

of self as being unequal to their current image of self, and for some this is not acceptable (Dildy, 1996; McPherson et al, 2001).

#### **2.3.2.2 *Disruption of relationships and the emotional burden***

Fluctuating degrees of disability and uncertainty about the future generate concern about harming significant relationships particularly within families and in situations where care and support are required (Bury, 1988). Concerns about not being a worthy partner or becoming a burden are common themes in the literature (Bath et al, 1999; Dildy, 1996; Ryan, 1996, Williams and Woods, 1988). Fear of losing independence has been identified as a main stressor in RA (Newman et al, 1996; van Lankveld et al, 1993) and the need to elicit help appears to be associated with mixed feelings of guilt, gratitude and anxiety (Bath et al, 1999; Brown and Williams, 1995; Williams and Wood, 1988). These issues have not been specifically explored in relation to pain in RA. Feelings of depression, low mood and/or frustration are common in patients' accounts (Bath et al, 1999; DeVillis et al 1997; McPherson et al, 2001). Frustration and anger are also mentioned in the literature in reference to patients' reflections upon functional constraints or limitation (Melanson and Downe-Wamboldt, 1995; Williams and Wood, 1988).

#### **2.3.2.3 *Medical care and illness***

Medical care is closely interwoven through the lives of those with RA, extending from the time of diagnosis onwards (Gray and Muirie, 2002; Harrison and Symmons, 2000). Patients learn to manage their medical regimes e.g. by taking medication, they learn to control symptoms, adjust routines or daily activities and act as their own illness manager (Brady, 1998). However, treatments themselves and medical regimes can be seen as a burden associated with adverse effects and discomfort (Bath et al, 1999; Goodacre and Goodacre, 2004; Katz, 1998; Mahat, 1997), concerns about treatment effectiveness and difficulties in making decisions about treatment options (Locker 1983; Melanson and Downe-Wamboldt, 1995).

### **2.3.3 *Searching for Meanings: making sense of life with illness***

Part of the 'work' of illness is to make sense of what is happening to the body and life, forming meanings that can be attributed to new experiences (Kleinman, 1988). It has been suggested by several authors that individuals'

views about causation have a particularly important bearing upon the meanings associated with illness as well as symptom-related behaviours (Blaxter, 1983; Sanders et al, 2002; Williams, 1984). Using various methods (e.g. surveys and structured interviews) patients' accounts of the aetiology of RA highlight how patients integrate medical knowledge about the disease into their accounts e.g. identifying causal factors such as inheritance, auto-immune and environmental factors (Affleck et al, 1987a; Brown and Williams, 1995; Kay and Punchak, 1988; Williams and Wood, 1986). Patients are also aware of the limits of medicine in fully understanding the cause of RA (Ailinger and Schweitzer, 1993).

Patients' views on prognosis in RA also reflect the medical view of RA, where RA is perceived to be a serious condition, that can lead to increasing disability and dependency, a condition where the course is unpredictable (Locker, 1983; Sakalys, 1997). Ideas about the limited ability of medicine to cure RA or to abolish its symptoms are also aligned with the medical view; acknowledging cure is not possible and that full control of symptoms is unlikely (Ailinger and Schweitzer, 1993; Kay and Punchak, 1988; Locker, 1983). That said, prescribed medications are valued, particularly disease modifying anti-rheumatic drugs (DMARDs) which are considered central to the management of RA (Goodacre and Goodacre, 2004), again aligned with the medical view (Fries, 2000), this being further manifested in patients' compliance with and knowledge of DMARD drugs and toxicity (Bath et al, 1999; Donovan and Blake, 1992; Kay and Punchak, 1988).

Integration of medical knowledge within patients' accounts is reflected in the importance patients place upon gathering information particularly relating to disease aetiology, progression and how it can be treated (Barlow et al, 1999; Bath et al, 1999; Bury, 1982; Neville et al, 1999; Williams and Wood 1986). Patients gather information related to RA from multiple sources; health professionals (often rheumatologists), friends, family, peers, magazines, books, internet and television (Barlow et al, 2002; Bury 1988; Donovan, 1991; Kay and Punchak, 1988; Newman et al, 1996).

### ***2.3.3.1 Integrating meanings of illness within biographies***

Understanding the nature of patients' illness-related meanings has been advanced through studies using in-depth interviews, attending to how accounts are given and examining meaning in its widest sense i.e. in relation to how it was constructed by the individual (Bury, 1988; Williams, 1984). In this way, the approach to the subject of

'meaning' is individualised, inviting the patients to tell their life story, paying attention to how the account was given and asking questions about why it has been given in that way (Bury, 1988; Williams, 1984). Whilst noting that some accounts appeared to present common-sense versions of science and medical knowledge others ventured into complex social, psychological and moral areas (Williams, 1984). Bury (1988) noted that patients' integrated accounts of their own experiences of the onset and progression of their illness in a number of ways that were complex and varied within biographies. In this way, each had a unique perspective; however, accounts were also reflective of society's expectations of particular illness. The interaction between illness experiences and the shaping of new meanings stresses the dynamic nature of meanings. Views of the world and new meanings are likely to be subject to change as the individual tests new meanings for acceptability for self, family and others in their social world (Price and Cheek, 1996).

### **2.3.4 Summary and Conclusions**

Pain and its consequences are situated amongst a multitude of varied concerns and challenges facing the patient with RA - a condition characterised by uncertainty, an illness having impact upon many areas of life; physical and emotional, personal and social. Pain is highlighted as being problematic from pre-diagnosis onwards, although it has not been explored in detail in general studies of patients' view of illness. Medical interactions, treatments and seeking information about disease and illness are integrated within patients' lives and, in part, inform patients' understanding of their illness experiences. Driven to find meaning in illness, to make sense of experiences, patients build upon medical knowledge and theories related to RA whilst incorporating personal features of their life as shaped by experiences and the wider influences of society and culture. Accounts of meanings of pain are likely to be changeable, embedded within varied individualised accounts, drawing upon a multiplicity of influences. Therefore, to fully explore the meaning of pain, attention should be paid to personal narratives, considering what is said and how it is said within the context of individuals' life courses and the context of the account generation, at the same time making comparisons with accounts from others. Understanding processes shaping patients' perspectives of pain will require, therefore, a broad interpretive framework to encompass the multitude of factors e.g. experiential, social and cultural.

## **3 CHAPTER THREE - STATE OF THE ART: CHRONIC PAIN AND RHEUMATOID ARTHRITIS**

### **3.1 INTRODUCTION**

The relative contributions of different disciplines and their varied approaches to studying and understanding pain are presented here. The aim is to highlight the complexity of the pain phenomena and the importance of patients' personal meanings of pain in shaping their pain experience and behaviours. Studies specifically related to RA are integrated, providing an overview of what is and is not currently known about pain in RA and identifying gaps in the literature. This information is also used to inform sampling criteria and presents the background for understanding the multiplicity of influences that may shape patients' and doctors' perceptions of pain, which will, in turn, inform interpretation of the findings. It is argued that the dominant, positivistic, scientific orientation towards the study of pain and clinical pain states promotes research in RA which sidelines or ignores the complexities of personal pain perspectives as well as the contextual, social and cultural influences that shape these perspectives. Current thinking about pain endorses an approach that is non-compartmentalised (Melzack, 1999) however, each pain-related research domain is presented separately here. This is to enable cognisance of what each contributes to understanding pain in RA and illustrates how they commonly remain distinct with regard to each other. Critical overview of four dominant research approaches identified within the pain-research literature are presented:

- Bio-scientific and biomedical research perspectives;
- Psychological and behavioural research perspectives;
- Sociological research perspectives;
- Cultural research perspectives.

### **3.2 BIO-SCIENTIFIC AND BIOMEDICAL RESEARCH PERSPECTIVES ON PAIN**

Historically, medicine and the natural scientific auspices were able to assert authority over the study and care of the body (including the study of pain) with the acceptance of a dualistic representation of mankind, where distinction is made between the mind and the body. Western medicine commonly attributes the origins of the conceptual split of 'mind' and 'body' to Descartes, who described the mind as a passive recipient of sensory

information projected from the periphery. In this way observable bodies could be separated from the private sphere of mental and moral life which remained within the church's authority (Sullivan, 2001). Scientific understanding of the person strongly influences medicine, although moral and cultural issues often permeate the latter (Salmon and Hall, 2003). Both bio-scientific and biomedical domains approach pain research with a reductionist perspective, where the pain experience is 'real' and therefore can be studied objectively, separate from the individual and the influences of society or culture. This positivistic framework or paradigm represents the strongest tradition in pain research (Carter, 1998). This framework upholds enquiry characterised by controlling what is observed, removing value judgements or biases that the researcher may introduce and seeking to determine rules/laws that predict events and govern the world (Higgs, 2001; Malterud, 2001a). Knowledge of pain in the areas of pharmacology, neurobiology and biochemistry has expanded using this type of positivistic, experimental approach and contributed to the development of current pain theories.

### **3.2.1 Scientific Pain Theory**

Significant advances have been made in understanding the mechanisms of pain generation and analgesia over the past 40 years (Woolf and Decosterd, 1999). Conceptions of pain as a direct and inevitable consequence of tissue damage have been surpassed with increasing acceptance of the Melzack-Wall gate control theory (Melzack and Wall, 1965) which was the first attempt to clearly define a potential mechanism of pain modulation. This theory suggested that the central nervous system could control or influence pain sensations associated with noxious stimuli. Accordingly, medical and biological sciences moved towards accepting the role of the brain as a system that could filter and modulate inputs related to the pain experience (Melzack, 1999). Over time pain theory developed as discoveries were made confirming that noxious input itself, if prolonged, could change the central nervous system, that emotions e.g. fear, and expectations and past experiences could influence pain (Dubner and Ruda, 1992; Turk et al, 1998; Vlaeyen and Linton, 2000). There is no universal agreement on a unifying pain theory (Morris, 2003). However, building upon the pain-gate theory, current models of pain integrate multiple inputs generating the pain phenomenon e.g. sensory inputs from somatic receptors in joints, cognitive and emotional inputs and intrinsic neural modulation (Melzack, 1999).



Progression of work to understand the stages of processing in pain and pain dimensions emphasises the importance of the individual's perceptions of the meaning and consequences of their pain experience (Price, 1999, p43-70). Wade et al (1996) proposes a four-stage model of pain processing (see Table 3.2.1).

**Table 3.2.1 Four Stages of Pain Processing (primary reference: Wade et al, 1996)**

Dimensions of Pain Processing	Description
1. Sensation • Sensory-discriminative	Encompassing the spatial extent, temporal and intensity related features of a painful sensation as well as discrimination of the pain qualities (e.g. burning, aching, throbbing), its location and duration.
2. Unpleasantness • Immediate unpleasantness	The immediate emotions associated with a painful sensation that generates a feeling of intrusion normally associated with pain as it poses a potential threat to the body.
3. Suffering • Cognitive-evaluative	The integration of the individual's cognitive efforts i.e. their evaluation of the pain and consequences of pain, influenced by memories and contextual features and most closely aligned with suffering.
4. Behaviour • Overt behavioural expression	Behaviour or actions (conscious or not) related to the pain experience e.g. guarding a limb, grimacing or resting ('down time') during the day.

The third stage of pain processing, conceptualised as 'cognitive-evaluative' factors, is most closely related to the individual's perception of pain, integrating cognitive efforts i.e. beliefs and evaluation of the consequences of the pain. This stage is bound to memories and contextual features and is significant to the patient and most closely related to the concept of pain as suffering (Fields, 1999). The key point from current thinking about pain is that pain mechanisms *themselves* produce pain symptoms and *not* the disease or causative agents, although these may be implicated in the initiation of pain mechanisms (Woolf and Decosterd, 1999, pS142). Common to current models of pain (e.g. Loeser 2000; Price, 1999) is the acceptance that the pain experience is more than a sensation alone, it is associated with unpleasant emotions, some immediate and others dependent upon further integration of the personal meanings of pain and context (Fields and Basbaum, 1999). Pain is mediated not only by internal, peripheral biological processes but is susceptible to modulation by contextual factors and emotions, as well as by higher level processing i.e. pain experiences are the end result of multiple processes at a variety of levels and are inherently personal (Turk and Okifuji, 2003).



### 3.2.2 Definitions and Classifications of Pain

Following from current pain theory it would appear impossible to separate the pain experience from personal perception or social influence. This is reflected in the widely accepted definition of pain from the International Association for the Study of Pain (IASP):

‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (Merskey and Bogduk, 1994, p210).

This acknowledges the personal as well as biological influences involved in the pain phenomenon. It also reinforces the subjective nature of pain, accepting that pain is ‘real’ when the individual reports it, including circumstances where there is absence of evidence of a pathophysiological cause. It is also acknowledged that the meaning of the word ‘pain’ is learned through life and experiences of injuries or illness, reinforcing the social and cultural influence in shaping the meaning of pain (Merskey and Bogduk, 1994).

Three broad classes of pain have been described - transient, acute and chronic (Loeser, 2000). Transient pain can be experienced without the presence of local tissue damage and is common in everyday life e.g. the short-lived pain of receiving an injection. When the stimulus is removed the pain ceases and because of this, it is not a complaint commonly associated with clinical medicine. Acute pain is associated with injury of the body tissues and with noxious events (e.g. injury or inflammation). The biological function of acute pain is to warn of impending or actual tissue damage, prompting the individual to avoid further harm e.g. guarding against using an arm when it is fractured. It is associated with the promotion of an interruption of activity followed by attention to the pain, to find its cause, and thus preventing further damage (Flor et al, 1990). Acute pain can be defined as a symptom that usually signals tissue damage, having an identifiable causal relationship between disease/injury and is limited in duration (Ready and Edwards, 1992 p2). Chronic pain is an umbrella term, the definition of which is often based upon a collection of symptoms, based largely upon clinical grounds rather than specific diagnoses (Chojnowska and Stannard, 2003). The definition below encapsulates the key characteristics of chronic pain:

‘pain that either persists beyond the point at which healing would be expected to be complete or that occurs in disease processes in which healing does not take place. Chronic pain may be accompanied by severe psychological and social disturbance. Those who do not have evidence of tissue damage can experience chronic pain.’ (CSAG, 1999, p2)

In medical and clinical texts RA is characterised as presenting with both acute and chronic pain types (Ready and Edwards, 1992; Simon et al, 2002). In acutely painful states (a 'flare') localised, painful, tender and swollen joints are associated with increased disease activity and inflammation in the presence of clinical markers of inflammatory processes. Ongoing daily pain experiences are associated with a combination of factors, a degree of uncontrolled synovitis, joint degeneration and deconditioning resulting in lowering the pain threshold (Falconer, 2001, Rice and Pisetsky, 1999). Ultimately the progressive nature of RA is perceived to exceed the body's capacity to restore itself to a 'normal' state and modern medicine is as yet unable to cure or fully control the disease, subsequently a chronically painful state emerges.

### 3.2.3 Pathobiological Mechanisms of Pain in RA

The biomedical study of pain in RA concentrates upon understanding or identifying the 'cause' of pain at the level of the body tissues i.e. pain is primarily perceived as a sensation arising from pathobiological mechanisms. This is emphasised in the IASP text on the Classification of Chronic Pain where RA is categorised as a:

'..generalised chronically painful syndrome [*where*] aching, burning joint pain [*is*] due to systemic inflammatory disease affecting all synovial joints, muscle, ligaments, and tendons' (Merskey and Bogduk, 1994, p 47).

Pain in RA, in biomedical terms, is presented as being fundamentally related to nociceptive mechanisms i.e. where the specialised primary sensory neurones (the nociceptors) are activated by noxious chemicals, mechanical or thermal stimuli (Woolf and Decosterd, 1999). This activity is related to the chronic inflammatory synovitis due to the chronic cellular immune response in RA, which characterises the disease (Dessein et al, 2000; Simon et al, 2002). This narrow, disease-oriented view obstructs consideration of how pain mechanisms themselves can modulate the pain experience. Pain associated with inflammation can sensitise the nociceptive system centrally and peripherally and if this continues over a period presents as a risk factor for pain chronicity itself (Jensen et al, 2001; Woolf, 1983). Clinical literature suggests that central neural sensitisation disorders in painful rheumatic diseases can become an important aspect of pathophysiology (Farrell et al, 2000; Mailis et al, 2001) and are evident in RA (Evers et al, 2001; Mannion and Woolf, 2000). These findings support an aggressive treatment approach towards pain to reduce compounding effects mediated by pain mechanisms (Pappagallo, 1999) using a wide range of pharmacological and non-pharmacological interventions (Moreland and St Clair, 1999; Simon et

al, 2002). Importantly, the focus of the treatment should not be confined to controlling the disease as disease processes may not necessarily sustain pain, although they are often implicated in initiating pain.

### **3.2.3.1 Summary and relevance of pain theory in RA**

Current pain theory advances the idea that multiple dimensions and diverse inputs shape the pain experience, emphasising the importance of individual's perceptions of pain and its consequences. These views can shape the individual's pain experience and behaviour and are most closely related to the emotional pain response and suffering. The biological basis of pain in RA, mediated via inflammatory processes, is undisputed, posing a threat to up-regulate pain systems and thus generate a chronic pain state i.e. pain is detrimental in its own right. It is, however, notable that disease processes may only play a part in the chronic pain experience as further modulation via psychological and/or behavioural means may prevail. The aggressive treatment of acute pain is therefore important and the long-term management requires a multi-faceted attack.

### **3.2.4 Charting the Sensory-Discriminative Dimensions of Pain in RA**

Many studies of pain in RA are directed at quantifying sensory-discriminative features of the pain sensation and rely upon measurement of pain intensity using the Visual Analogue Scale (VAS) and McGill Pain Questionnaire (MPQ, see Appendix 3.1). These add to knowledge of the nature of pain intensity, quality and variability whilst, concomitantly, illustrating some of the complexities of pain in RA that *cannot* be addressed using these measures.

#### **3.2.4.1 Pain intensity in RA**

Numerous studies have investigated patients' perceptions of the intensity of pain in RA, using VASs (e.g. Bingham et al, 2002; Covic et al, 2000; Coster and Bengtsson, 2001). For those with established RA (diagnosed at least one year) mean intensity ratings vary from 38.8 (Katz, 1998) to 78.1 (Hurst et al, 1997). Variations can be ascribed to a number of factors i.e. varied sampling methods, but taken together, and supported by findings from verbal scales, they show self-reported pain intensity in RA is moderate to severe (Clark et al, 2003; Kosinski et al, 2000).

Although simple measures of current pain intensity are shown to be sensitive and reliable (Melzack and Katz, 1999) they conceal a complexity of the pain experience in RA (Clark et al, 2002). Williams et al (2000) explored the nature of chronic pain patients' interpretations of the ratings they had selected from simple pain rating scales using qualitative interviews. Patients offered a diverse range of factors that influenced their self-rating of pain intensity:

- intra-person comparisons of 'usual pain' with 'worst pain';
- consideration of what others may think of their pain rating; and
- concern about feeling a fraud where their pain rating is low but they are requesting help.

This emphasises the complexity of diverse personal meanings, which incorporate social and intra-personal evaluations that can be concealed by simple quantifying tools. Williams et al (2000, p463) suggested that closer attention must be given to examining the processes involved in the creation of the meaning of pain and to explore shared social meanings of pain, a task not yet undertaken in the study of RA.

#### **3.2.4.2 Pain qualities in RA: sensory and affective descriptors**

Continuing to focus upon pain sensation dimensions several researchers have investigated the types of words selected by patients with RA, making use of the McGill Pain Questionnaire or modifications of it. The most commonly selected adjectives to describe pain in RA are: aching, throbbing, burning and tiring (Gaston-Johansson and Gustafsson, 1990, Leavitt et al, 1986, Charter et al, 1985, Wagstaff et al, 1985). A strong affective language response is noted in RA, selecting both sensory and affective words to describe pain e.g. burning and exhausting (Burckhardt, 1984; Leavitt et al, 1986) tiring, sickening or fearful (Charter et al, 1985; Radanov et al, 1996; Gustafsson et al, 1999). This hints at higher processing and interpretation of impact of pain or consequences and it has been ascribed to patients knowing that their condition is chronic and progressive, therefore the patient fears what their pain may mean in terms of progression (Charter et al, 1985). However this has not been further explored.

### **3.2.4.3 Pain location and temporal distribution**

Common sites of pain in RA are located at the hands, wrists, feet, knees and shoulders (Badley and Papageorgiou, 1989; Leavitt et al, 1986; Wolfe, 2003). Estimates of the average number of painful joints sites at any one point in time vary from 4.7 (Papageorgiou and Badley, 1989) to 6.7 (Katz, 1998). Pain in RA can be periodic, persistent, re-occurring and continuous (Johnson and Repp, 1984), commonly fluctuating throughout the day (Gaston-Johansson and Gustafsson, 1990). A prospective study of the temporal sequencing of joint pain in RA concluded that it would be impossible to characterise the distribution of daily self-reported joint pain in RA due to significant differences in the patterning (Affleck et al, 1991). Pain is also reported through the night (Gaston-Johansson et al, 1990; Rojkovich and Gibson, 1998) for a proportion of patients but studies are rare and the relationship between sleep disturbance and pain in RA remains unclear (Stone et al, 1997).

### **3.2.4.4 Summary**

Clinical research approaches to pain in RA attempt to quantify the pain experience in RA. These have focussed upon sensory-discriminative dimensions and show pain to be moderately intense to severe, variable and unpredictable. Pain is reported at multiple sites and is associated with a strong affective component. Limitation encountered with the use of standardised measures (e.g. VAS or MPQ) bring to light the inherent complexities of personal pain experiences since they fail to capture patients' diverse perspectives on pain, concealing or constraining personally relevant meanings. Such studies of pain in RA are reflective of the narrow biomedical focus regarding what pain is for the individual, concentrating upon what is considered measurable (e.g. pain intensity) with less consideration of subjective or personal pain meanings. Pain study in scientific and biomedical contexts consider pain as a sensation rather than an emotional, evaluative phenomenon with personal and social implications.

## **3.2.5 Correlation Studies of Pain in RA**

A wealth of scientific effort has targeted the study of the inter-relations between reported pain intensity and measures of body function, disease status and environmental factors. Findings suggest that there is a relative lack of relation between disease measures and pain reports and suggest that diverse factors modulate the pain

experience, factors that are relevant to this study's sampling procedure. This type of research also underlines the deleterious impact of pain upon biological and psychological health and quality of life.

#### **3.2.5.1 Pain, disease activity and duration**

It might be anticipated that there would be a relatively close association between patients' self-reported pain intensity and indicators of disease activity, as patients commonly locate pain at sites known to be affected by the disease e.g. synovial joints of the hand (Gaston-Johansson and Gustafsson, 1990; Jayson, 1999). However, when measures reflective of disease activity e.g. ESR (see Appendix 1.1) number of swollen joints or radiological tests are compared with pain intensity ratings the evidence is equivocal with most studies suggest that disease factors can only explain a moderate variation in pain intensity (Flor and Turk, 1988; Gaston-Johansson and Gustafsson, 1990; Smedstad et al, 1995; van Lankveld et al, 1993). Other studies report there is no correlation between pain intensity and disease indicators (Coster and Bengtsson, 2001; Hewlett et al, 1995).

Studies of pain intensity and disease duration produce mixed findings with equal numbers suggesting positive and negative relations (Barlow et al, 1999; Roche, 1998; van Lankveld et al, 1993). This may be explained by more sophisticated interactions existing between disease duration and age (Koutantj et al, 2001). Cross sectional studies of pain and duration become complicated as increasing age is associated with a trend towards increased pain intensity reports (Jakobsson and Hallberg, 2002). In contrast, significant correlations between pain and negative psychological status (i.e. anxiety and depression) have been well documented (Brown et al, 2002; Sharpe et al, 2001). Other factors related to pain rating include, educational level (van Lankveld et al, 1993; Young et al, 2000) and multiple psychosocial factors e.g. social support, psychological constructs related to coping and control with illness and pain (discussed in Section 3.3.4). In conclusion, disease measures e.g. indices related to disease activity and the number of swollen joints (commonly used in clinical research trials and clinical care) are not strong surrogate measures for the pain experience, even at the singular level of intensity dimension. Self reported pain intensity in RA appears to be multi-faceted and complex, failing to be predicted by objective measure of body state or disease activity but more closely related to psychological and social factors.

### **3.2.5.2 Pain, socio-economic deprivation and educational level**

Increasing pain intensity is associated with indicators of deprivation in RA (Young et al, 2000) which may be related to the finding that those who are more socio-economically deprived have worse outcomes in RA (e.g. greater disability, Hamilton et al, 2001; McEntegart et al, 1997). Greater educational attainment is associated with lower intensity pain ratings (van Lankveld et al, 1993; Young et al, 2000). The complex relation between educational achievement, pain and disability has received attention for chronic pain populations (Callahan et al, 1992; Leigh and Fries, 1991; Roth and Geisser, 2002). It suggests the negative association between schooling and disability is complex and interacts with a variety of other variables.

### **3.2.5.3 Pain and negative affect**

Pain is an aversive experience and therefore the association between negative emotions and use of affective words to describe pain in RA is not unexpected (Gustafsson et al, 1999). Emotional distress has been described as, 'the most undesirable feature of painful experiences', and can present as fear, anxiety, anger or depression (Craig, 1999, p331). Numerous studies have been conducted investigating the relationship between pain and depression in RA and those with RA are twice as likely to be depressed when compared with the general population (Dickens and Creed, 2001; Smedstad et al, 1995). Higher levels of pain are associated with depressive symptoms and anxiety in RA (Brown et al, 2002; Sharpe et al, 2001; Smedstad et al, 1995). The direction of relations between negative affect and pain is thought to be bi-directional, increasing pain being associated with increasing depressive symptoms and vice-versa (Dickens and Creed, 2001). The mechanisms underlying these relations are complex and not clearly defined but it is suggested that there are roles for cognitive, behavioural and physiological mechanisms (Huyser and Parker, 1999).

There is a paucity of research investigating emotions of frustration, fear and anger in RA despite its recurrence in accounts of illness experiences (Melanson and Downe-Wamboldt, 2003; Ryan, 1996). The onset of acute pain is associated with provoking fear and anxiety as the individual contemplates their well being (Craig, 1999). Anger is reported in studies of patients with other chronically painful conditions (Fernandez and Turk, 1995; Greenwood et al, 2003). Lack of enquiry into emotions and RA pain may be due to the transient nature of acutely painful states or the likelihood of non-participation at these times. Rheumatoid arthritis is characterised by both



acute and chronic pain states and it is likely that patients experience a range of negative emotions, which would appear not to have been thoroughly explored.

#### **3.2.5.4 Pain and gender**

Generally pain is reported to be greater and more varied for women and evidence suggests the basis of this lies in the complex interplay of genetic, physiological, hormonal, neural, social and cultural factors (Berkley and Holdcroft, 1999). In early RA there are no significant differences between men and women's ratings of pain intensity (Smedstad et al, 1995). However, in established disease women would appear to rate pain more intensely (van Lankveld et al, 1993), although this is confounded by disease being more severe in women (Ollier et al, 2001). Gendered views about pain within society suggest differences between the expectation of men and women's ability to tolerate pain and variability in the expression of pain (Bendelow, 1993; Kleinman, 1988). For all of these reasons it is relevant to have both males and females in the sample group.

#### **3.2.5.5 Pain, disability, quality of life and health status**

Patients' reported pain level is found to be one of the best explanatory factors for disability in RA (Lindquist, 2002) and studies consistently show pain intensity ratings to be significantly, positively correlated with disability (Bingham et al, 2002; Mahat, 1997). These findings are supported with findings from sub-sets of health status variables where increased pain scores are associated with poor physical functioning, lower mobility and self care scores (Dwyer, 1997; van Lankveld, 1993). Assessment of subjective health and quality of life bring evaluations of health and illness closer to the patient's perspective and arguably provide the most pertinent view in clinical medicine (Brown and Gordon, 2004; Sullivan, 2003). Patients with RA have been shown to have a lower quality of life (QOL) than those without the condition (Borman and Celiker, 1999). Increasing pain has been associated with decreasing QOL for those with RA (Lambert, 1985; van Lankveld et al, 1994). Patients' assessment of pain is found to be more closely related to changes in disease specific health related QOL measures than clinical measures of the disease i.e. joint swelling and tenderness counts (Kosinski et al, 2000). This provides added support to the claim that there is a closer link between patients' perceptions of their pain experience with constructs closely aligned with patients' concerns (e.g. QOL) in comparison to disease variables.



### **3.2.5.6 Pain as a priority for treatment and improvement**

A study of 58 female patients with RA found pain was identified as the poorest health status dimension (Minnock et al, 2003). Pain status was associated with the lowest levels of satisfaction with regard to health with 68.4% of participants prioritising pain as the dimension of health that most needed improvement (Minnock et al, 2003). Patients consistently rank pain as a priority for treatment (Anderson et al, 1994; Cox et al, 2000; Heiberg and Kvien, 2002) and identify pain as a main illness stressor for at all stages of illness (Melanson and Downe-Wambolt, 2003; van Lankveld et al, 1993).

However, these studies may present an over simplified view of pain perspectives having used inflexible questionnaires or lists of problematic symptoms for patients to select from. A recent qualitative study of patients' perspectives on important treatment outcomes suggested that the relative importance of identified outcomes e.g. pain and disability, may change with time and situation e.g. 'flare' state versus non-flare state (Carr et al, 2003). This concurs with other studies using similar methodologies who reported that pain may only be a priority for treatment upon first consultation, becoming less important at later stages (Stafford and Cox, 2001). A non-questionnaire-constrained study found pain to be rated third most important for treatment after functional disability and issues of dependence (Taal et al, 1993). This requires further exploration.

### **3.2.6 Summary and Conclusions**

The extensive body of knowledge about pain in RA from scientific and biomedical studies is predominately generated from cross-sectional research of sensory-discriminatory dimension of pain and other measurable variables. Constrained by using relatively simple measurement tools (e.g. VAS) these studies fail to incorporate user-defined constructs of pain and fail to capture the influence of personal, biographical, contextual or social dimensions of pain. However, they do present data relevant to this study. The detrimental impact of pain upon the physiological and psychological health of patients is emphasised and more importantly patients' perceive pain to impact negatively upon their quality of life and health status. This is reflected in their prioritisation of pain for treatment. In addition, this work refutes the simplistic view that patient perceived pain intensity in RA is primarily related to disease activity. Pain cannot be adequately assessed through surrogate measures of disease activity. Studies demonstrate the complexity of interaction between multiple factors influencing pain and the variability of individuals' experiences. Factors that should be taken into account in sampling, where the aim is to

generate a diversity of accounts, should include both males and females, varied age, sociodemographic and educational status and interview those at different stages of illness. Neglected areas of pain study in RA are identified i.e. emotions and pain, changing priorities regarding pain with time and/or circumstances/experiences.

### **3.3 PSYCHOLOGICAL AND BEHAVIOURAL RESEARCH PERSPECTIVES ON PAIN**

#### **3.3.1 Introduction**

Research into psychological and behavioural factors influencing how an individual will experience and adapt to illness and symptoms has become one of the most active areas in RA research. Initial studies of chronic pain and arthritis considered personality or unconscious processes to be responsible for causing pain or the response to pain. This view has now been rejected in the absence of evidence (Keefe et al, 2002a; Skevington, 1986) and the individual is now considered as an active thinker, self-aware, able to appraise their situation, in ways that influence their illness experience and ability to adapt (Weinman and Petrie, 1997). Empirical work in this field has identified strong relationships between patients' perceptions of illness and symptoms e.g. beliefs about pain and how they behave, adapt and experience symptoms (Groarke et al, 2004; Keefe and Bonk, 1999). Particular constructs have been the focus in RA studies: helplessness, self-efficacy and coping and the study of relations between these and health related outcome e.g. psychological health. The broader framework from which this work was developed identified five important dimensions of illness perceptions related to the response to illness: illness identity, cause of illness, consequences of illness, time-line and ideas about control or cure (Scharloo et al, 1998, see Table 3.3.1 for descriptions of each component). These dimensions serve as useful headings to allow summarisation and identification of gaps in knowledge regarding pain perceptions in RA. Limitations of the methodologies used and presentation of how this work can inform sampling is also presented.

**Table 3.3.1 Five Dimensions of Illness Perception Representing the Cognitive Organisation of any Illness**  
(primary reference Scharloo and Kaptein, 1997, p105).

Illness Perception	Definition
Illness Identity	A person's perception of the problem, it can be identified by its label (e.g. a diagnosis of RA), visible signs or symptoms (e.g. a deformed joint).
Cause of Illness	Relates to how the individual makes sense of how they came to have the disease.
Consequence/s of the Illness	Reflects the person's perception of the potential impact of the disease e.g. physical disabilities, financial losses and emotional impact (both in the short and long term).
Time-line	Relates to what the individual expects regarding the duration of the illness, its course e.g. protracted versus short-lived.
Control or Cure	Views about what can be done medically regarding disease or illness, or what the individual can do for themselves e.g. can they fully recover from the disease or can they influence the course of the illness and outcome?

### 3.3.2 Illness Identity in RA

The meaning that patients ascribe to their pain experiences are inherently related to their conceptions of the condition with which they have been diagnosed e.g. pain in osteoarthritis (Sanders et al, 2002) or repetitive strain injury (Reid et al, 1991). Patients diagnosed with RA have a strong illness identity (Weinman et al, 1996), identifying pain as a key dimension of the illness experience (Lorig et al, 1984; van Lankveld et al, 1994). This parallels with general conceptions of arthritis within western society where arthritis is regarded as a painful, progressive, condition of the joints (Badley and Wood, 1979; Price et al, 1983). Patients with RA consider they have an enhanced understanding of arthritis and RA compared to the general public (Barlow et al, 2002). However, when their overall knowledge of the disease is assessed it appears limited (Hill et al, 1991; Minnock et al, 2003). These studies of patients' knowledge of RA have not illuminated what is known of how patients make sense of pain as these studies focus upon overall knowledge of disease e.g. drugs, exercise, energy conservation, tests etc.

Views of pain change with time and experiences (Bury, 1988; Williams, 1984) but little reference is made to conceptions of ageing and pain in RA. Arthritis is understood within western society as a condition related to ageing and many anticipate that 'wear and tear' arthritis will affect them in later years (Price et al, 1983).

Additionally, research suggests that older people perceive pain and disability to be a normal part of growing older (Blaxter, 1983; Charles and Walters, 1998; Griffith and Carr, 2001). Sakalys (1997) reported upon the pre-diagnostic symptom attributions of patients with RA and found a number (not specified) of patients attributed symptoms to ageing. Whether patients with RA integrate ageing concepts within their pain explanations is not known but would appear to be relevant to healthcare because, where pain is viewed as being a 'normal' part of ageing, this acts as a barrier to seeking medical help (Sanders et al, 2002 and 2004).

### **3.3.3 Patients' Perspectives on the Cause of RA and Flares**

Patients' accounts of reasons for the onset of RA mix biographical details with lay understanding and experiences (Bury, 1982; Williams, 1984). Patients have their own theories of pain pre-diagnosis (e.g. pain due to injury, Donovan et al, 1989) but how these change with time and what factors shape them is not known. It is anticipated that lay views of arthritis (Price et al, 1983) and medical information gathered after diagnosis (Bath et al, 1999; Barlow et al, 2002) would influence how patients think about pain. However, RA patients give accounts deviant from the medical view (e.g. regarding the cause of RA, Affleck et al, 1987a). Studies of patients with non-disease related chronic pain have found that when patients' pain-beliefs deviate from the scientific view this is associated with increased psychological distress, poorer therapy compliance (Williams and Thorn, 1989), maladaptive cognitions and heightened disability (Geisser and Roth, 1998).

Given the unpredictable and fluctuating nature with which symptoms present in RA it is notable that few studies have investigated patients' perceptions of the causes of the exacerbation of symptoms, which are a recognised source of distress (Brown and Williams, 1995). Affleck's (1987a) study is the exception, investigating patients' attributions associated with flares of their condition. Psychological stress (45%) changes in weather (34%) and excess physical activity (34%) were given as the most common causes of symptom flares, with reduction in symptoms associated with medication change (49%) and the absence of psychological stress (21%). As pain is strongly identified with the illness identity, when considering variation of symptoms then it would be anticipated that explanations would be related to disease activity fluctuation; however, patients offer explanations of psychological stress and their own activities as factors. Such beliefs may have implications for help seeking behaviour where increased pain is routinely not associated with worsening disease.

### **3.3.4 Perceptions of the Consequences of Pain/Illness and Coping with Pain**

The consequences of pain in RA are often contained within studies examining generalised accounts of patients' perspectives upon illness impact as a whole (reviewed in Section 2.3). The consequences of chronic pain are discussed in depth in Chapter Four.

#### **3.3.4.1 Coping with Pain in RA**

The strategies used by patients with RA to cope with pain is recognised as an important variable in understanding how individuals adjust to living with RA (Keefe et al, 2002b). The Coping Strategies Questionnaire (CSQ; Rosenstiel and Keefe, 1983, see Appendix 3.3) is one of the most commonly used measures of pain coping strategies with six items assessed; diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, catastrophizing, praying or hoping and increasing activity level. Studies using the CSQ have shown that those scoring high on pain control and rational thinking have lower levels of pain and disability (Beckham et al, 1991; Parker et al, 1989).

Models that incorporate assessment of coping strategies used by patients to deal with pain generally make a distinction between active and passive strategies. These refer to the degree with which the patient relies upon internal (active) and external (passive) control to manage pain. Active coping in RA (e.g. information seeking, pain control and rational thinking) is associated with less depression, increased function and less pain. In contrast; passive coping (e.g. self-blame, catastrophizing, focusing on pain, restricting social activities) is associated with greater pain and flare up activity, depression and functional impairment (Brown and Nicassio, 1987; Covic et al, 2000; Manne and Zautra, 1992; Smith and Wallston, 1992). These studies convincingly identify that varied ways of thinking about and dealing with pain can influence health related outcomes; however, they do not explain the complexities of an evolving illness and changing pain experiences. The investigation of 'general' coping styles is reported for times when patients perceive they have 'moderate' amounts of pain when using the CSQ (Smith et al, 1997). This raises questions about what the patient conceives as moderate pain, what is worse and least and how perceptions of pain and strategies to deal with it change under different circumstances. Interview based studies of coping in RA suggest that patients use different strategies dependent upon activities and context (Blalock et al, 1993) and research suggests that patients may cope differently dependent upon their age and the severity of pain (Watkins et al, 1999).

The cross-sectional nature of these studies examines the coping characteristics of groups, rather than the individual's specific status (i.e. incorporating age, disease duration, varying stages of illness). Therefore the associations between ways of dealing with pain and experiences are not discernible. Those few who have attempted delineation of patient and disease variables (within-person) have concluded that research investigating illness and coping is most informative when situational and personal factors are integrated (Watkins et al, 1999). Large and Strong (1997) explored the personal constructs of coping for those with chronic low back pain, exploring what 'coping' meant to individuals. A diversity of facets not integrated with psychological formulations of the concept were revealed, integrating social and cultural elements e.g. not being a burden, being cheerful and outwardly stoical. These suggest a wider influence than is traditionally incorporated in empirical studies. Novel factors are not integrated within measurement tools used to assess dimensions of coping and therefore may be overlooked.

#### **3.3.4.2 *Pain and the influence of social support and relationships***

How a spouse reacts to their partner's behaviours can influence their reports of pain and function and shape how an individual manages pain (Kraaimaat et al, 1995; Manne and Zautra, 1989). Relations between couples and levels of perceived social support can all influence psychological health and quality of life for those with chronic pain (Doeglas et al, 1996; Fitzpatrick et al, 1991; Kerns et al, 1990; Newman, 2000). For these reasons the sampling strategy should aim to recruit individuals with varied social circumstances.

#### **3.3.5 Patients' Perspectives on the Progression of RA**

Patients identify RA as being chronic in nature and understand the disease activity to be cyclical or fluctuating throughout its course (Ailinger and Schweitzer, 1993; Kay and Punchak, 1988; Skevington, 1993). Relations between these expectations of chronicity and conceptions of pain have yet to be explored. This oversight is perhaps surprising given that patients' repeatedly identify associations between the emotional burden of RA and concerns about increasing dependency with time (Bath et al, 1999; Newman et al, 1996; Ryan, 1996). Episodes of incapacitating pain would be expected to be highly emotive given expectations of chronicity and the uncertainty regarding the length of an episode in association with concerns about dependency (Bath et al, 1999; Dildy, 1996; Ryan, 1996; Williams and Woods, 1988). The lack of connection between knowledge of the

affective components of pain in RA and knowledge of illness conceptions may be resolved through exploration of pain narratives examined for individual evaluations of different pain experiences and associated interpretive frameworks.

### **3.3.6 Patients' Perspectives on Control and Treatment of RA and Pain**

Patients' accounts of RA correspond with the medical view, that RA can be neither cured nor fully controlled (Ailinger and Schweitzer, 1993; Kay and Punchak, 1988). Perceived control of pain in RA has received much attention following from early work where those who perceived control over daily symptoms were more 'adjusted' to their illness and had more positive mood (Affleck et al, 1987b). Relations between psychological constructs of helplessness and self-efficacy are most developed.

#### **3.3.6.1 *Pain, self efficacy and helplessness***

The concept of self efficacy is thought to be an important dimension which captures an element of how patients adjust to chronic pain and refers to the confidence that the individual has in being able and capable of achieving a particular goal (Weisenberg, 1999). Patients who have high levels of self-efficacy tend to be more active, less depressed and report lower levels of pain (Parker et al, 1995; Smarr et al, 1997). Helplessness is a state where individuals do not believe that their efforts will be successful and that outcomes will be negative (DeVillis and Callahan, 1993). Using measures of helplessness designed for arthritis populations, high levels of helplessness are related to reports of pain in activities of daily living (Callahan et al, 1988) and are associated with negative psychological states and poor functional ability (Roche, 1998; Tennen et al, 1992;). In a longitudinal study of RA pain over six years, helplessness was at least as important as disease factors in predicting current pain levels; in addition, a sense of helplessness to avoid the experience of pain in RA was particularly significant (Roche, 1998).

Both helplessness and self-efficacy are learned through experiences (Keefe et al, 2002) but current research does not identify what experiences shape thoughts about the ability to control pain nor examine concurrent levels of patient knowledge and educational need. Other work suggests patients' cognitions may not just lie with ideas about 'self' but extend to others e.g. social cognitions about others not caring about their pain (Gil et al, 1990).



Ryan (2003b) used qualitative methods in an effort to identify factors that patients perceived influenced the control of the symptoms of RA. Four major categories were identified:

1. Reduction of 'physical' symptoms e.g. pain and stiffness;
2. Social support matching patients' perceived need;
3. Provision of information;
4. Characteristics of the medical consultation.

Ryan's (2003b) concept of control was based upon patients' perceptions of events/behaviours that promoted positive outcome and introduced novel dimensions e.g. information provision and patients' perceptions of doctors' degree of knowledge of interventions and their confidence in them. This study extends the nature of control related perceptions although it stops at the level of describing patients' accounts of what influenced them in how they lived with symptoms of RA and fails to develop arguments as to how these influences might come about. The study is also flawed in its use of a convenience sample of patients, recruited from a rheumatology clinic, who were interviewed at that same site by one of the rheumatology nurses working within the unit (although not directly involved in the patients' care).

### **3.3.6.2 *Perceptions of Treatment for RA and Pain***

After diagnosis patients' hopes for relief of symptoms (Donovan et al, 1989) are moderated, with fewer than 25% expecting pain relief and improved function (Ailinger and Schweitzer, 1983). Psychological studies of control of pain have focused upon personal control cognitions or appraisals rather than perspectives on the nature and role of specific treatments and expectations of them (Horne, 1997; Horne and Weinman, 1999). There is, therefore, a glaring deficit in RA research as long term pharmacological treatment is the cornerstone of management (Fries, 2000).

Clinical investigations relating to medication in RA have focused upon clinical issues of medication adherence and willingness to accept risk (Fraenkel et al, 2002; Ho et al, 1998; Horowicz-Mehler et al, 2002; O'Brien et al, 1990; Park et al, 1999; Pullar et al, 1990). Donovan and Blake (1992) provide the most extensive exploration of patients' views regarding varied pharmacological treatments in inflammatory arthropathy based upon interviews and consultation observations. Nearly 50% of the 54 participants were non-compliant, most limiting the number



of prescribed drugs they took (particularly NSAIDs and analgesic drugs) for fear of side effects. Patients' concerns about the toxicity of DMARD therapy is well recognised (Bath et al, 1999; Fraenkel et al, 2002; Goodacre et al, 2002) but these concerns appear to be countered by perceptions of the drugs importance in limiting joint damage and maintaining quality of life (Goodacre and Goodacre, 2004).

Goodacre and Goodacre's (2004) in-depth study of patients' beliefs about disease modifying anti-rheumatic drugs (DMARDs) advanced the understanding of the complex and reasoned interpretive frameworks constructed by patients with RA. Factors thought to influence conceptions of medication were reported i.e. the influence of stages of treatment and longer-term projections of effect, experiences of side effects and symptom relief. Other work suggests that patients' views of medication are influenced by their perception of health professionals' attitudes towards drugs (Goodacre et al, 2002). This concurs with others' findings that patients make treatment choices based upon the responses of doctors as well as personal beliefs and values, applying their own initiatives in balancing negative views of medications with prescription and perceived benefits (Kelly-Powell, 1997; Lumme-Sandt and Virtanen, 2002). The lack of studies exploring patients' views on analgesics is unexpected given that they are frequently prescribed in RA (Moreland and St. Clair, 1999). This may be a reflection of the focus upon the management of RA being centred on the use of DMARDs (Kwoh et al, 2002). Donovan and Blake (1992) suggested that health professionals might incorrectly assume that patients are knowledgeable about analgesics and fail to give them required information/advice. In contrast, giving written and verbal advice about DMARDs is promoted as normal practice (SIGN, 2000) and may, inadvertently 'encourage' patients to view analgesics and other non-DMARD therapies as relatively unimportant.

In contrast to research in rheumatology, recognition of the under-treatment of pain in cancer (Glajchen, 2001) provides a rich source of patients' representations of analgesic medications (Paice et al, 1998; Thomason et al, 1998, Ward et al, 1993, Ward and Gordon, 1996, Yates et al, 2001). Patients with cancer strongly identify with concerns and fears about analgesic medication being addictive, ideas of tolerance developing with continued use and side effects. Other factors related to pain in cancer are highlighted within these studies that do not appear in the RA literature e.g. beliefs about tolerating pain and expectations that pain could not be better controlled than it is (Paice et al, 1998; Thomason et al, 1998, Ward et al, 1993, Yates et al, 2001). Patients with cancer appear to also consider social-relations i.e. believing that good patients do not complain and that complaints of pain may distract the doctor from attending to the disease management (Ward et al, 1993; Yates et al, 2001).

Parallels between cancer and RA pain issues may appear misguided as each disease entity has specific, associated pain meanings. However, like cancer patients, patients with RA expect and anticipate pain (Lorig et al, 1984; Turk et al, 1998; van Lankveld et al, 1994) and are as likely as those with cancer to believe that they have little or relatively low levels of control over their illness (Felton and Revenson, 1984). These factors are relevant to patient care as cancer studies have shown that patients with more patient-related barriers to pain management (e.g. negative beliefs about analgesics, expectations of pain) present with higher pain levels (Gunnarsdottir et al, 2002). Adherence to drug regimes or prescriptions are also influenced by balancing views about the necessity of medications to maintain or improve health balanced against concerns about adverse effects e.g. addiction or side effects. When patient concerns are found to be greater, adherence to medication prescriptions is lower (Horne, 1997; Horne and Weinman, 1999).

### **3.3.7 Summary and Conclusions**

Research in the psychological and behavioural domain is successful in identifying key constructs and variables (e.g. social relationships, pain beliefs) that are influential regarding adaptive living with RA and variable pain experiences. Measurement tools have assisted in determining the prevalence of and relationships between beliefs and behaviours for large populations, leading to the development of interventions successful in reducing the pain reports and improving health outcomes. However, the use of the tools to measure patients' attributions, separated from life histories and personal narratives mean there are difficulties in connecting social and experiential factors (e.g. roles and relationships, environmental/contextual) to cognitive factors. As predetermined constructs are the basis of the measures this is likely to obscure any personal meanings of pain or how the individual interprets pain and limits understanding of the phenomenon. A move is needed from the 'intro-psyche perspective' (Leventhal et al, 1997, p36) to generate a more comprehensive understanding of pain that is genuinely patient-centred and not driven by any one discipline's pre-defined and potentially restrictive constructs. Studies of pain in RA have concentrated upon understanding issues of control and coping and have sidelined dimensions that would appear important to patients' conceptions of pain e.g.:

- How pain conceptions may change with ageing and time;
- Beliefs about treatments (especially analgesia);
- Potential barriers to pain reporting;

- The influence of social relations (e.g. with doctors);
- The environment or context of pain behaviours.

### **3.4 SOCIOLOGICAL RESEARCH PERSPECTIVES ON PAIN**

#### **3.4.1 Introduction**

There are two key approaches to studying illness/pain within the sociological research domain, the 'outsider' and 'insider' orientations (Conrad, 1987). The former refers to examination of factors 'outwith' the individual's personal view of illness e.g. how gender influences pain experiences. This type of sociological approach has not been significantly developed in the pain field (Bendelow, 2000) since the early work of Zborowski (1952) and Zola (1966) exploring social variations in the way pain was interpreted by different ethnic groups. In contrast, more recent approaches have seen movement towards understanding the personal meanings of illness/pain and studying relations with the socio-cultural world of the individual (Bendelow et al, 2000; Corbin and Strauss 1987; Sanders et al, 2002). The 'insider' perspective locates the subjective experience at the centre of the inquiry, subjectivity is valued and inductive methodologies and complimentary qualitative research methods are employed. The respondent is viewed as an active thinker and pain viewed as a lived, embodied experience. Meanings of pain and how culture and society may shape these are at the centre of enquiry (Bendelow and Williams, 1995). A metasynthesis of insider views on chronic pain is presented in Chapter Four. This section focuses upon the few 'outsider' social influences regarding illness behaviour and pain meanings that originate from medical sociological studies. These contribute to understanding the social dimensions that may shape pain meanings and related behaviours.

#### **3.4.2 Gendered Views about Pain**

Gender is both biologically and socially constructed. Women are known to report pain more often than men and present with a wider range of pains (Price, 1999, p65-69). However little work has been conducted exploring how socialisation and cultural views might influence gendered views about pain (Johansson et al, 1999). Bendelow's (1993 and 2000) study of pain and gender explored how conceptions of gender could shape pain beliefs. Exploring men's and women's meanings of pain, Bendelow reported that greater stigma was associated with

emotional or psychological pain than the more 'legitimate' constructions of physically originating pain. This hierarchy of pain credibility was most distinct in men's accounts. This concurs with observations that it is more common for individuals to express pain or distress in somatic or physical terms than psychological ones (Johansson et al, 1996; Salmon and May, 1995). Patients (male and female) are known to make efforts to present their pain in a credible (i.e. in a somatic sense) and with warrant (Johansson et al, 1996; Werner and Malterud, 2003). The presentation and attribution of distress/pain in somatic terms rather than psychological terms is understood to be a reflection of the nature of interactions between patient and society and the medical environment, where psychological illness can be stigmatised (Sullivan, 2001, p153).

### **3.4.3 Private Pain Versus Public Pain**

A group's social or cultural background not only influences how they respond to pain experiences but also whether they communicate/express their pain to others (Lasch, 2002). Two types of pain behaviour, private pain and public pain, are described by Helman (2000, p128). Private pain refers to the individual choosing not to communicate their pain experience to others; no verbal or non-verbal clues are given. Public pain refers to translation of a private, inner pain experience to the public domain, communicating pain verbally or non-verbally in a way that is influenced by socio-cultural and psychological factors. Sullivan (1999 and 2001) endorses the importance of pain expression as the critical social dimension i.e. the inter-subjective action that has a purpose beyond simply conveying an internal state, something learned with time and expectations of the response of the audience.

Disclosure and concealment of pain is found in accounts of chronic pain suggesting the person with pain is conscious that the audience is critical regarding what is said and not said. Therefore, the individual considers how he/she will be judged, thus introducing a moral dimension to pain expression (Hilbert, 1984; Kotarba, 1983). Insights from RA narratives suggest that pain is concealed in certain circumstances e.g. not wanting to burden family (Bury, 1988; Locker, 1983). In the clinical context there is also suggestion that patients' discriminate between what accounts are deemed appropriate for the specialist nurse (e.g. psychosocial concerns) and rheumatologist (e.g. drug issues, Ryan et al, 2003b). Whether the expression of pain experiences and particular consequences are compromised in the clinical setting is not known and further inquiry is therefore warranted as pain assessment is dependant upon patient reporting (Rutledge and Donaldson, 1998).

### **3.4.4 Sick Roles and the Experience of Chronic Pain**

Parson's concept of the 'sick role' represents an important link between the social systems and illness experiences affecting both patients and the doctors (Parsons, 1951 cited in Scambler, 1997, p47). The sick role importantly identifies that the state of 'being sick' has both personal and physiological connotations but is also socially defined by cultural views i.e. the rights and responsibilities of an individual who is ill. These views shape what that individual may be expected to do (i.e. to want to make efforts to recover) and what they can be rightfully excused from e.g. work. Parson's model is applicable only to acute or time-limited illness and not chronic illness, as the individual will not necessarily recover fully from their 'sick' status (Turner, 1996, p103-105). However it is useful in reinforcing that there are social and culturally based ideas about what is socially and morally accepted as right and wrong in relation to being ill. It is expected that some of these influences would be apparent in study of the pain phenomenon in RA.

Within patients' accounts of living with RA are references to their perceptions of what is socially acceptable and unacceptable when living with a chronic illness. Patients express the concern that, as their level of disability can fluctuate day-to-day, they may be seen as malingers and make attempts to conceal their difficulties and as act as 'normal' (Bury, 1988; Locker, 1983; Wiener, 1975). Patients with RA also identify things they should do, or be seen to do, in relation to self-care and medical care e.g. complying with medical treatments and through adapting and accommodating to life with RA (DeVillis et al, 1997; Locker, 1983). How much social and moral influences affect constructions of pain and pain behaviour in RA is not known. However, related social issues of legitimacy, responsibility and blame are prominent in other chronically painful conditions (reviewed in Chapter Four) and require cognisance in the interpretation of RA patients' accounts.

### **3.4.5 Contexts of Healthcare and Pain**

Organisational structures of healthcare influence patient experiences (Griffiths, 2003), however, there are few studies that explore how contexts of healthcare shape pain conceptions. One study of different healthcare contexts in Puerto Rico and New England found each had its own values and organisational systems which impacted upon healthcare professionals' responses to patients with chronic pain (Bates et al, 1997). Others' findings suggest that even within specialist centres, within the same country, pain can be conceptualised differently by health professionals (Vrancken, 1989). No studies were found regarding conceptualisation of pain in relation to current

rheumatological care in the UK. The study of clinically orientated pain-meanings in RA (for both patients and doctors) may give insight into contextual healthcare influences.

### **3.4.6 Summary and Conclusions**

Socialisation and social contexts may influence what people are prepared to say/do about pain and how they conceive of pain personally and as a member of a social group. Exploration of socially defined constructs (e.g. the sick role) helps make sense of people's experiences of illness but can be criticised for failing to allow integration of how body experiences inter-relate with these factors (Kelly and Field, 1996). The 'out-sider' views of pain fail to capture the sense of how patient's pain experiences interact with socially defined morals in illness, ideas about responsibility etc. Individuals' accounts of pain need to be considered both for what they say directly (e.g. pain engenders social isolation) and how social factors may shape their explanations (e.g. moral obligations not to burden others). Narratives about pain expression or concealment in different contexts and with varied audiences may advance understanding about how social and cultural influence impact upon the construction of personal pain meanings.

## **3.5 CULTURAL RESEARCH PERSPECTIVES ON ILLNESS AND PAIN**

### **3.5.1 Introduction**

Culture is a broad concept including 'systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the ways that human beings live' (Kessing, 1981 in Helman, 2000, p2). Culture therefore influences ways of expressing and giving meaning to pain, permeating patients' local worlds of social relations and personal experiences of pain (Good, 1992; Kleinman et al, 1992b). Current approaches to studying pain and culture use a variety of methods, often narrowing the focus on culture to constructs of ethnicity or race (Edwards et al, 2001; Riley et al, 2002). It has been established that different cultures have varied perceptions of pain experiences, different pain beliefs and responses (Lasch, 2002; Morris, 2001; Riley et al, 2002). The few cultural studies of pain in arthritis that were found, similarly focused upon comparison of ethnic groups (Creamer et al, 1999; Jordan et al, 1998). This section considers the characteristics of the systems of meanings and the

nature of lay understanding of pain within western medicalized society, as a factor that may shape patients' account of pain in RA.

### **3.5.2 Lay Understanding of Pain in Western Cultures**

'Lay' refers to the shared beliefs or shared culture of those who are not medically trained or the non-expert, e.g. beliefs that are not directly attributable to medical knowledge but which are culturally or personally located (Gillespie, 1995; Helman 2000). As a member of a particular society, the individual is guided by the prevailing culture, giving them a particular worldview, influencing their experience and behaviour with respect to others (Helman, 2000).

The category of 'western culture' is subsumed by a number of different dimensions and can be summarised as follows (Turner, 1995, p35):

- the secularisation of culture, where the religious beliefs and symbols have lost their public dominance;
- intellectualisation and scientific procedures and 'ways of knowing' become dominant in the public domain; and
- an elevation of the importance of systems of individual discipline and regulatory bodies.

Western cultures uphold the importance of medical models, which relate to the body and disease, and medicine is viewed as powerful and scientific (Helman, 2000; Rey, 1993). In this way, pain stories are not unique but share basic features within western societies and understanding of pain draws upon assumptions of the dominant scientific, biomedical view of the body and symptoms (Aldrich and Eccleston, 2000; Honkasalo, 2000; Peters et al, 1998; Radley, 1994; Scarry, 1985).

### **3.5.3 Accounts of Everyday Pain**

There are few studies which explore how culture shapes pain and make use of rigorous research methods (Lasch, 2002); however, there are a few exceptions. Aldrich and Eccleston (2000) studied accounts of everyday pain from individuals with diverse backgrounds (including those with chronic illness). They found the dominant account of pain was that it signified malfunction or damage to the body. This damage or injury required repair and was



associated with perceived need for action to ameliorate or abolish pain. Pain was also conceived as a diagnostically useful symptom, mirroring its status in clinical medicine (Sullivan, 1999). The respondents did not always hold doctors responsible for the management of pain as personal responsibilities to care for the body were voiced (Aldrich and Eccleston, 2000). This supports Morris' (1991) proposition that western society adopts an organic model of pain, where pain is conceived narrowly, associating pain with nociceptive processes e.g. where pain is result of the transmission of 'painful sensations' through the nervous system indicative of tissue damage. Pain is associated with notions about injury or body dysfunction, disease or invasion or a threat to the integrity of the body (Leder, 1984-1985, p 259). There is a shared belief that pain is a warning signal that will cease when the body is recovered or healed (DeGood and Shutty, 1992) and that pain is time limited and can be successfully treated (Hilbert, 1984). This aligns explanations of everyday pain with normative lay conceptions of the body in western society i.e. the body is viewed as something that is discrete and machine like; an entity that can go wrong (Kleinman, 1988, Stainton Rogers, 1991).

Lay explanations of pain could be interpreted as a simplified understanding, one that fails to integrate current pain theory which proposes that biological/physiological factors can become secondary to social and psychological factors in shaping pain (particularly relating to the chronic pain experience, Melzack, 1999). Accounts of chronic pain meaning have been explored in relative detail for those with non-defined diagnoses and these are critiqued in Chapter Four. The limited literature regarding patients with RA and their pain conceptions are also integrated within Chapter Four.

### **3.5.4 Summary and Conclusions**

In western cultures the medical and scientific worldview of pain has strongly shaped and provided definitions and understandings of pain incorporated within society. Lay conceptions of pain are reflective of basic biomedical understanding of pain, where pain is viewed as a signal of malfunction or damage to the body tissues. Therefore pain is associated with being diagnostically useful, possibly requiring medical treatment, the expectation being that pain will resolve or will be cured. This organic model of pain is still used as a framework for interpretation in some chronically painful states and is fully discussed in Chapter Four. How closely accounts of pain in RA reflect dominant lay views of pain have not been explored. The cultural influence is rarely integrated within biomedical research (Ware and Kleinman, 1992); however, an understanding of the dominant lay view of pain



provides a critical perspective for analysis of how western cultural conceptions of pain may shape both patients' and professionals' perceptions of pain in RA.

### **3.6 SUMMARY AND CONCLUSIONS - CHAPTER THREE**

Current theories explain how the unpleasant experience of pain can arise in the absence of any apparent tissue damage and can be influenced by a wide range of biological, personal, social-cultural and contextual factors. Pain models emphasise the critical role of personal perceptions of pain and its consequences in shaping the pain experience and behaviours. This is particularly evident in chronic illnesses where cognitive-evaluative dimensions of pain heighten the role of non-nociceptive factors in modulating the pain experience. This is substantiated in RA where disease activity is found to account only moderately for pain reports, with instances where psychological and social factors can be more closely related to pain than disease measures. However, the pathobiological basis of pain in RA is not disputed and biomedical study highlights the risk posed by inflammatory processes in sustaining chronic pain in RA, supporting both the aggressive treatment of pain and the importance of patients reporting their pain. The narrow focus of biomedical studies of pain in RA upon sensory-discriminative dimensions may sideline the patients' perspective. However, these are valuable in emphasising that, although RA treatment has advanced, patients with established RA continue to experience moderate to severe pain at multiple sites which present in unpredictable ways and, most importantly, impacts negatively upon their quality of life and functioning.

Psychological and social approaches to pain in RA have confirmed the importance of cognitive efforts (e.g. self-efficacy) and social factors (e.g. social support) in shaping patients' pain behaviours and degrees of success in adapting or coping with pain. However, their respective 'intro-psychic' and 'out-sider' views of pain and methods of investigating pain result in a failure to connect the socio-cultural and cognitive factors. Empirical studies separate the person and their experiences from the context whilst constraining the researcher to use defined pain constructs and measures (e.g. VASs). This does little to further understanding of how cultural, social and experiential factors shape perceptions of pain, pain behaviour and pain consequences and thus silences patients' personal perspectives on pain. The processes or influences that shape actions or behaviours or beliefs are left unexplored and unexplained. New studies emphasise the social, cultural and contextual influences that may shape pain perceptions, areas under-explored in RA: emotions and pain, changing priorities with time,

ageing and pain, beliefs about treatments for pain, barriers to reporting pain and the influence of relationships and contexts. These studies also inform sampling. For diverse pain accounts the sample requires: varied age, gender, educational level, socio-economic background, time since diagnosis/duration of RA, perceived levels of function/severity of RA, levels of social support and varied experiences of healthcare.

## **4 CHAPTER FOUR - INSIDERS' VIEWS OF PAIN: A METASYNTHESIS**

### **4.1 INTRODUCTION**

A significant body of research has built up over the past twenty years of insiders' perspectives on chronic illness experience i.e. exploring the patient's narrative or story about their illness (Pierret, 2003). The patient's view has returned as an important source of information and understanding as chronic illnesses become more prevalent and issues of care are more prominent than cure (Gerhardt, 1990). Subjective meanings ascribed to illness and the ways that individuals experience illness are primarily explored using qualitative methods (often semi-structured interviews) to generate narratives or stories i.e. a means by which patients actively give meaning to experiences, based upon individual and cultural resources (Garro and Mattingly, 2000; Hydén, 1997). Within this chapter qualitative research studies exploring pain meanings from the individual's perspective are critiqued. Studies are drawn from varied fields exploring non-cancer, chronically painful conditions e.g. low back pain, osteoarthritis and RA. Findings from these studies are synthesised and the main themes emerging, related to insiders' perspectives on pain, are presented and referred to again in the discussion. Gaps within the literature (most notable in relation to RA studies) and methodological weakness, identified in the majority of studies critiqued, are presented as further justification for the aims of this study.

### **4.2 METASYNTHESIS - DEFINITION AND AIMS**

Metasynthesis is an interpretive, systematic effort to bring together and re-examine findings and discover the key themes related to a diverse topic e.g. pain in chronically painful conditions (Finfgeld, 2003). It provides a means of building upon existing qualitative findings and knowledge, a feature not evident in existing studies of the chronic illness experience in RA (e.g. Bath et al, 1999; Brown and Williams, 1995; DeVillis et al, 1997; Persson et al, 1996, Ryan, 1996). By including studies of those with and without formal medical diagnosis patients' chronic pain experiences and understanding are examined together as a broad category rather than as distinct groups defined by diagnoses. Exploration of both the specifics of disease-defined studies as well as examination of the whole group of qualitative, chronic pain studies is advocated in progressing knowledge of chronic pain

(Conrad, 1987; Encandela, 1993). By considering the shared/contrasting features of pain meanings within and outwith RA studies, the interpretive possibilities can be built upon existing knowledge in all related areas.

There is as yet no formally accepted 'best strategy' for synthesising qualitative findings as it remains a relatively new concept and various types of metasynthesis are found (Finfgeld, 2003). Metasynthesis is defined here as 'descriptive' i.e. the findings are not deconstructed but involve synthesis of the findings from qualitative studies based upon chronic pain patients' accounts of pain and pain related issues (Schreiber et al, 1997). Each study included in the metasynthesis is critically examined for what and how it contributes to the whole area of enquiry and findings are compared and contrasted. The aims of the metasynthesis are:

- To review the nature of the findings within the literature related to insiders' perspectives on the meaning of chronic pain (e.g. shared explanations and personal meanings);
- To examine how pain has been conceived within studies of insiders' perspectives on pain i.e. elucidate the primary concepts and patterns within this field of study; and
- To determine the state of knowledge as a whole and identify any gaps existing regarding patients' perspectives on non-cancer, chronic pain and particularly in RA.

#### **4.3 METASYNTHESIS METHODS**

Searches were performed using several electronic databases (CINAHL, PsychLIT, MEDLINE and the SSCI) for the years 1990-2004, English written only (see Appendix 4.1 for the search-terms used). Citations were searched for any key materials published before 1990 and these were included where they satisfied inclusion/exclusion criteria listed in Table 4.3.1.

Each study was systematically assessed for the following key features: sample characteristics, frame of reference (or paradigm), methods used, the level of processing of the findings, quality control strategies and the nature of the findings (Sandelowski and Barroso, 2003; Schreiber et al, 1997; Thorne et al, 2002). These features were tabulated for each study, organising studies by their sample characteristics (i.e. whether there was a medically identified diagnosis or not, see Appendix 5.1).

Studies were then re-read asking the following questions of each (adapted from Thorne et al, 2002):

- What are the key themes emerging from the studies identified when findings are compared and contrasted?
- What theories or perspectives have researchers adopted when studying insiders' perspectives on pain and how might that have influenced the body of knowledge generated?
- What methodological frameworks have been used in these studies and how might they have shaped the findings?
- What are the characteristics and type of findings generated?
- What is known and not known about insiders' perspectives on pain and in particular pain in RA?

**Table 4.3.1 Inclusion and Exclusion Criteria for the Qualitative Metasynthesis Study**

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**Inclusion Criteria**

- Insider orientation to pain i.e. patients' stories/accounts of pain are the primary data source, no pre-defined constructs or measures used to frame the data collection i.e. studies are qualitative and interpretive in nature.
- Studies' subjects are adults with non-cancer or non-malignant chronic pain (including conditions with and without medically defined cause e.g. non-defined chronic back pain).
- The subject of pain is the substantive topic and main focus of the study (e.g. pain experiences or explanations of pain).
- Studies present demographic data regarding the sample or individual case.
- Inclusion of illustrative information supporting the findings (i.e. quotations).

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**Exclusion Criteria**

- General studies of the 'illness experience' of RA or other painful conditions, where pain is not discussed as an individual topic and where other symptoms or co-morbidities may contribute to illness experiences.
  - Where subjects' pain is associated with mental illness.
  - Where subjects studied are living in non-western cultures.
- 

## **4.4 CHARACTERISTICS OF THE STUDIES IN THE METASYNTHESIS**

A total of 24 studies were included, originating from the UK, USA and Scandinavian countries. Researchers were from mixed disciplines: psychology, clinical health science, sociology and anthropology. Correspondingly, perspectives and methodologies were varied - generic, qualitative-interpretive, phenomenological and phenomenological-hermeneutic. Sample sizes ranged from 4 to 75 with most averaging around 20 participants. There was a preponderance of studies with all female samples or with significantly more females than males. Socio-economic and demographic characteristics were not always fully described although there was generally

details of age range and pain duration. The most commonly studied groups were those with non-specific or medically undefined chronic pain (e.g. chronic LBP) in comparison to those diagnosed conditions (e.g. RA or osteoarthritis).

Inclusion of RA studies was limited to four (Bury, 1988; Locker, 1983; Ryan et al, 2003b; Shaul, 1995 and 1997) as much of the qualitative research in RA was wide in its coverage of the RA experience and correspondingly limited in coverage of pain meaning and experiences (e.g. Bath et al, 1999; Brown and Williams, 1995; Dildy, 1996; McPherson et al, 2001; Melanson and Downe-Wamboldt, 1995; Nemchand, 1997; Ryan, 1996; Wiener, 1975). However, as these excluded studies have pain issues embedded within them, these points are integrated with the metasynthesis findings where appropriate to highlight under-explored issues. To denote where these are presented they are referenced in *italics*. It is notable that Locker's (1983) and Bury's (1988) studies are comparatively old (interviews having been conducted in the late 70s and early 80s. Locker's (1983) study is in book format and presents the most extensive description of pain conceptions, however, sampling was restrictive with all 24 adults diagnosed at least 10 years with high levels of disability (17 were housebound). This may not be relevant to how patients talk about pain experiences but is relevant to views on RA management since treatment approaches and outcomes have changed significantly over the past two decades (Fries, 2000; March and Lapsley, 2001).

With the exception of Thomas (2000) none of the studies provided a definition of what 'chronic pain' was. All inferred that as subjects were recruited from pain clinics or had a chronically painful condition e.g. fibromyalgia, they therefore had 'chronic pain'. The words 'pain' and 'chronic pain' are used interchangeably within the section related to key themes identified as the lay person or patient does not use the term 'chronic pain' in their accounts i.e. 'pain' is undistinguished from acute or chronic classification. However, the author makes the distinction where relevant in discussion sections.

## 4.5 METASYNTHESIS FINDINGS

Three main types of findings were identified and grouped as follows:

1. Shared meanings of pain within society and within sub-groups of pain patients i.e. those describing the nature of patients' understanding or explanations of pain;
2. The consequences of living with chronic pain i.e. presentation of the lived or existential views of chronic pain;
3. Clinical-contextual meanings of pain i.e. patients' perspectives in relation to medical interactions and pain management topics.

### 4.5.1 Shared Meanings of Pain: understanding and explaining pain

Two main themes were identified that could be subsumed within the category of 'shared meanings of pain', 1. biomedical accounts of pain and, 2. the varied credibility of 'body' pain and 'psychological' pain. Both these themes are reflective of dominant accounts of pain within western societies, although accounts of how these changed with time and experiences suggests a more complex frame of reference.

#### 4.5.1.1 *Biomedical accounts of pain*

Patients were all driven to find an acceptable and credible explanation for their pain experiences (Honkasalo, 2000; Hilbert, 1984). Pain always had to signify something and finding the cause was an important grounding for the meaning of pain, particularly when patients were without a diagnosis (e.g. where their pain problem had only been labelled symptomatically i.e. low back pain (Hilbert, 1984; Johansson et al, 1999; May et al, 2000; Osborn and Smith, 1998; Walker et al, 1999). Patients gave accounts of pain as a signal of an underlying lesion/pathology or having a mechanical cause; in essence signalling something 'going wrong' with the body (May et al, 2000; Osborn and Smith, 1998). This corresponds to commonly presented explanations of pain within western society (Radley, 1994; Rey, 1993; Scarry, 1985). These explanations are concurrent with the biomedical view, where pain is associated with tissue damage and pain experiences are relative to nociceptor activity (Hanson and Gerber, 1990). Patients clearly integrated this reductionist model of pain within their accounts, often focusing on bodily representations of pain (Johansson et al, 1999; Söderberg et al, 1999).

'Often it [*the pain*] is so circumscribed that I feel, if it could be surgically removed, I'd be healthy.' (Honkasalo, 2000, p202, part in italics not in original)

The quotation above infers that pain has a peripheral site and physical cause located within a body part, using biomedical, causal explanations of pain. Although this strong theme recurs, even for those without any biological or organic evidence for their pain, narrative analysis of individual accounts illustrate a greater complexity, where patients interweave references to daily occurrences and events with biomedical terms and theories (Honkasalo, 2000). The complexity of patients' conceptions of pain are noted with narratives often containing conflicting accounts of pain, some influenced by context and peers, lay explanations or health professionals (Jackson, 1994). However, there is little consensus regarding what processes or influences support the ongoing negotiation and varied interpretations of pain as most studies focus upon describing common themes from the sample group and fail to attend to the personal, developmental narratives on pain.

In contrast, those researchers who present expanded individual accounts to illustrate their findings suggest that understanding of pain changes with experiences and interactions (particularly with healthcare professionals), diagnoses and time (Bury, 1988; Hellström, 2001; Honkasalo, 2000; Jackson, 1994). Sanders et al's (2002) biographical study of older people with OA shows them accepting that painful and disabled joints are 'normal', explaining this through concepts of ageing and disease duration. This contrasted with younger participants who did not accept their painful symptoms as part of their life course. This illustrates the potential importance of time, age and stages of illness on pain conceptions for the individual.

Patients with RA are known to actively construct an understanding of their illness in a pseudo-scientific way, integrating experiences, their diagnosis and medical explanations into their accounts (Bury, 1988; Locker, 1983). Medical explanation may suffice for accounting for the presence of pain but the patient appears not to fully comprehend the basis of symptom variability, describing it as a mystery and searching for understanding (Locker, 1983; Shaul, 1997). Patients offer explanations of associations with physical activity levels, psychological stress and weather as factors that may influence pain experiences; however, these have not been explored further (Locker, 1983; Affleck, 1987a). Patients' assumption that pain is an expected characteristic of RA (Bury, 1982) appears to have pre-empted in-depth exploration of how patients make sense of day-to-day pain in RA along with who or what might influence this.



#### **4.5.1.2 *The varied credibility of body pain and psychological pain***

Within western cultures and everyday discourse, pain is predominately perceived as 'physical pain', or 'real' pain i.e. pain associated with body damage, as opposed to the concept of mental or emotional pain where pain is related to emotional stress or mental illness (Bendelow, 2000). Similarly, those with chronic pain most commonly describe their pain as physical pain, which is also associated with greater kudos and validity than psychological/mental pain (Henriksson, 1995; Howell, 1994; Kugelman, 1999; May et al, 2000). Accordingly, patients presented strong resistance to notions of their pain being influenced by psychological factors (May et al, 2000; Werner et al, 2004). Howell (1994) suggested that it was important for patients to have their pain acknowledged both by themselves and others as 'real' or physical, as a necessary condition to allow women to successfully adapt to life with chronic pain. Health professionals were perceived as key providers of pain validation or invalidation and without that legitimisation of their pain women attributed their pain to psychogenic origins, or felt that health professionals were suggesting their behaviour was elicited for secondary gain (Howell, 1994). Osborn and Smith (1998) presented women's accounts of living with low back pain (with no organic, treatable pathology). They found repeated reference to concerns/distress related to not having the legitimacy of their pain experience established via objective means. When patients perceived that health professionals considered their pain to be psychogenic or doubting the real nature of their pain, this was described as threatening - a negative experience. These findings are supported in several other studies, all of which sampled patients with un-defined pain (Johansson et al, 1999, May et al, 2000, Werner et al, 2004; Werner and Malterud, 2003). Issues of health professionals legitimising patients' pain are discussed further in Section 4.5.3.1.

### **4.5.2 The Consequences of Living with Chronic Pain**

#### **4.5.2.1 *Loss and limitations and making adaptations in the face of pain***

At a descriptive level the practical, everyday consequences for the individual are well documented in phenomenological explorations of the pain experience. Common themes emerged related to pain interfering with multiple dimensions of living - work, social and family life; pain having a negative affect upon valued activities and roles e.g. as a mother, carer etc. (Johansson et al, 1999; Paulson et al, 2002; Seers and Friedli, 1996). The limitations or losses related to pain pervaded all aspects of life and were comprehensively listed by Howell (1994, p 106) - losing physical and mental abilities, work, family roles, friends, spiritual life and independence.

Depression or low mood was associated with the constraints upon individual's roles and function (Howell, 1994, Kugelman, 1999, Honkasalo, 2000; Locker, 1983; Sanders et al, 2002; Thomas, 2000). In addition to this the individual was faced with new efforts to manage pain, e.g. integrating medical treatments, forcing adjustment and adaptation within life to accommodate pain (Henriksson, 1995; Johansson et al, 1999; Kugelman, 1999; Seers and Friedli, 1996; Söderberg et al, 1999).

Reference to actual strategies for coping with RA are well documented and commonly relate to accommodating for pain e.g. reducing activity, pacing and planning, use of analgesics, re-defining activity, adapting or modifying activity (Bury, 1988; Locker, 1983; Shaul, 1995 and 1997). However these are not exclusively focused on pain and may be complicated by other symptoms or co-morbidities e.g. fatigue.

#### ***4.5.2.2 Suffering with pain - pain threatens 'self'***

The experience of chronic pain is associated not only with bodily limitation and the impact that has upon living and is greater than the sensory component but is conceptualised as threatening the sense of self, associated with suffering. Suffering is often used as a synonym for pain although they are theoretically distinct e.g. an individual can have pain related to a sprained ankle and not suffer (Morris, 2003). Suffering can be defined as a threat to the integrity of self, the result of a lack of consistency between what the individual expects of self and what he/she is (Cassell, 1982; Chapman and Gavrinn, 1999). 'Self' is a socially constructed concept; the individual's organised attributes that are established through time (Charmaz, 1983, p170).

Persistent pain states are associated with a loss of coherence of self through a variety of means which act to erode the individual's sense of who they are in comparison to who they were and what they had hoped for in the future. Table 4.5.2 summarises key themes that contribute to 'threatening self' in the chronic pain experience. The most conspicuous factor related to this most personally significant consequence of pain, is the socially dependent nature of suffering i.e. suffering is related to the individual living with and amongst others, with all their interactions and relationships. Equally notable is the prominence of accounts of being discredited by healthcare professionals. The overall sense of having a less valued sense of self is reflected in accounts of a resistance to leave behind images of a past world and self (Honkasalo, 2000) and negative comparison of current self with an idealised past-self (Osborn and Smith, 1998; Thomas, 2000).

**Table 4.5.2 Themes related to the Threatened Sense of Self in Chronic Pain**

Themes	Descriptor/examples	Supporting References
Isolation	<p>Pain isolates the sufferer from others who are unaware of their enduring pain experience (the private nature of pain)</p> <p>Physical isolation and introversion due to limited capacity to successfully participate socially</p>	<p>Hilbert, 1984 Honkasalo, 2000 Howell, 1994 Kugelman, 1999 Osborn and Smith, 1998 Paulson et al, 2002 Rhodes et al, 1999 Thomas, 2000 Walker et al, 1999</p>
Feeling Discredited	<p>Not having pain experiences validated or legitimised by healthcare professionals eroding sense of valued self. Associated feelings: stigmatised, blamed, shamed, humiliated, distrusted</p> <ul style="list-style-type: none"> <li>Minor theme: discredited by friends or family (Hellström, 2001; Locker, 1983; Shaul, 1995 and 1997)</li> </ul>	<p>Hellström, 2001 Henriksson, 1995 Hilbert, 1984 Honkasalo, 2000 Howell, 1994 Johansson et al, 1999 Rhodes et al, 1999 Seers and Friedli, 1996 Shaul, 1995 &amp; 1997 Söderberg et al, 1999 Thomas, 2000 Walker et al, 1999 Werner et al, 2004</p>
Living a Restricted Life	<p>Constrained opportunities day-to-day and for the future due to perceived lost capacity or function and limitation of valued role performance/s</p> <p>Loss of certainty regarding the future self</p>	<p>Bury, 1988 Henriksson, 1995 Honkasalo, 2000 Howell, 1994 Johansson et al, 1999 Kugelman, 1999 Locker, 1983 Paulson et al, 2002 Sanders et al, 2002 Seers and Friedli, 1996 Söderberg et al, 1999 Thomas, 2000</p>
Minor Theme • Fear of Pain	<p>Fear, distress associated with uncontrollable pain (associated with severe pain experiences)</p>	<p>Hellström and Carlsson, 1996 Locker, 1983 Sanders et al, 2002 Shaul, 1995 &amp; 1997 Thomas, 2000</p>

Studies of RA do not present enough descriptive detail to discuss their relationship with the key themes related to suffering identified in the main body of 'insider' pain studies and requires further exploration. However, the related themes of fear of pain and helplessness to effect any change on pain was reported in two RA studies

(Locker, 1983; Shaul, 1995 and 1997) and only mentioned briefly in others (Hellström and Carlsson, 1996; Sanders et al, 2002). Locker (1983, p34) described patients' accounts of pain associated with a deterioration in their overall condition and an inability to cope with a pain experience that was becoming increasingly intense, as associated with fear and/or helplessness to change pain. Similarly, accounts of severe pain in osteoarthritis are associated with patients' perceived lack of control and concern that the pain would take over the individual's life (Sanders et al, 2002). The lack of attendance to this in other studies may reflect a lesser pain variability or relate to an over-attendance to description of how pain limits function and roles; thus, neglecting the importance of the threat to the body that pain poses. As 'body' pain is the reason for seeking help in RA (Bury, 1988; Locker, 1983) it would have been anticipated to be a more prominent theme and requires further study.

In the field of chronic illness experience extensive work has been undertaken to understand the processes and influences that enable those with illness to progress to a point where the value of self is re-ordered and life positively re-defined (Charmaz, 1983; Corbin and Strauss, 1987). Table 4.5.2.1 outlines the processes that are integral to patients finding new and positive meanings in chronic illnesses.

**Table 4.5.2.1 Important Factors in Enabling the Individual with Chronic Illness Find New Meaning (primary reference, Corbin and Strauss, 1987)**

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Processes Integral to Re-defining 'Self' in Chronic Illness

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- Adapt and modify performances to accommodate and adapt to illness in life.
  - To have a degree of understanding of the illness and acceptance of how life is with illness and the consequences of it (now and in the future).
  - To find a new identity that is valued and adjust concepts of self in light of new possibilities i.e. new or re-defined roles.
  - To find new directions for the future.
- 

There are a limited number of accounts of how the individual with chronic pain re-defines life or finds a new valued self. Instead studies have concentrated upon accounts of the problems, difficulties and concerns of patients who find their lives overall diminished by pain (Hellström, 2001; Hellström and Carlsson, 1996; Hilbert, 1984; Johansson et al, 1999; Kugelmann, 1999; Osborn and Smith, 1998; Rhodes et al, 1999; Seers and Friedli, 1996; Söderberg et al, 1999; Walker et al, 1999; Werner and Malterud, 2003). Howell's (1994) grounded theory study of women's varied transitions through life with chronic pain provides a rare and most detailed account of how

some individuals came to have 'a fulfilled life with pain' (p111). Prior to moving towards the 'healthy phase of life' with pain, patients learned to share the burden of their illness, maximise use of pain relieving techniques, accepted their limitations, re-defined roles and had committed to 'making the best of it'. Shaul (1997) described a similarly veined study of the route to 'mastery' in RA incorporating many of the same factors e.g. finding effective ways to control symptoms, gathering new knowledge about the disease and how to live with it, finding sources of support and help, re-defining roles and relationships. However, Shaul (1997) did not focus specifically upon pain for the main body of the study and failed to show how different stages of life with RA inter-connected but listed the of stages of illness, suggesting a linear model. Movement from 'Becoming Aware' to 'Mastery' appeared as a seemingly simplistic process unlike the descriptors of the variable and unpredictable nature of the illness (Affleck et al, 1991; Gaston-Johansson and Gustafsson, 1990). More focused, Ryan et al's (2003b) study of patients' perceptions of what enables them to gain a sense of control over symptoms in RA reinforces the importance of gaining symptom control, social support, information about RA and care. These positive ways of living with pain require greater attention.

#### **4.5.2.3 Acceptance and tolerance of pain**

This theme does not occur in many studies as it only applies to the diagnosed groups, but it is dominant in them. Acceptance of pain in life is a recurrent theme in studies of patients with OA, a degenerative, progressive condition (Dickson and Kim, 2003; Sanders et al, 2002). Patients expected pain with older age, associated with the nature of the illness and related to patient tolerance of painful and debilitating symptoms i.e. pain was accepted and tolerated as a normal part of ageing (Dickson and Kim, 2003; Sanders et al, 2002). This definition of acceptance is distinct from the psychological definitions of 'pain acceptance' which refer to the decisions made by patients with chronic pain to engage in activities in spite of pain (McCracken et al, 2004). Despite the caveats of Locker's dated study e.g. sampling only severely disabled patients, it is the only study that specifically makes reference to changing conceptions of pain with time and concepts of acceptance and tolerance of pain in RA. A woman's description of her pain highlight this (p31):

'I've got it [RA], I'm not going to get rid of it, so I've just got to get on with it and that is the way that I accept arthritis.. You see, arthritis is a painful thing so you grow to accept that. The pain doesn't worry me too much now, I just say a few expletives and carry on with what I'm doing.'

The patient's reasoning that her pain experience should be accepted related to the belief that the condition will be painful, progressive and not amenable to medical or self-treatment. Notions of being realistic are identified by patients with RA as being important in being able to cope with or thrive in spite of their illness (Swift et al, 2001). Whether this 'realism' has relevance for perceptions of pain and action or inaction in seeking help or self-management in current times is not known.

### **4.5.3 Clinical-Contextual Meanings of Pain**

The nature of chronic illnesses requires that many patients have regular contact with health professionals, for review of status and treatments/interventions. Doctors and medicine are perceived as the authority on pain, hence themes emerge in patients' accounts that were evidently related to diagnostics, responsibility for pain management/treatment and pain related patient-doctor interactions. Clinically orientated studies aim to further understand patients' views about clinical experiences in relation to what they consider to be problematic issues e.g. studying patients' accounts of experiences at pain clinics to aid understanding of, 'the origins and nature of the negative attitudes exhibited by many back pain patients..' (Walker et al, 1999, p621). In this way clinical-contextual meanings of pain emerge. The term 'context' is used in varied ways in qualitative research e.g. from environment, to ambience or immediate relevant situation. Here, context refers to a general frame of reference that the individual uses to situate their talk about pain in relation to medical or clinical care and related interactions (Hinds et al, 1992).

#### **4.5.3.1 Doctors legitimising pain and patients' self identity**

Legitimacy is a concern that others accept or acknowledge the distress or difficulty the patient experiences (Locker, 1983 p131). The desire for an acceptable diagnostic label given by a credible authority figure is a recurrent theme in accounts of chronic pain. This is proposed as a means to protect self-identity, establishing worthiness as a person and establishing a positive moral vision of the individual with pain (Hellström, 2001; Honkasalo, 2000; Johansson, et al, 1999; Werner et al, 2004). The doctor is asserted as the key provider of diagnosis, a powerful medical meaning of pain, giving credibility and validity to the patients' pain experience and complaint, hence legitimising their presentation (Johansson et al, 1999; Seers and Friedli, 1996; Söderberg et al,

1999, Werner and Malterud, 2003). Alternatively, the lack of attachment of a defined medical diagnosis can cast doubt on the legitimacy of symptoms e.g. as reported in fibromyalgia (Henriksson, 1995; Söderberg et al, 1999). A stigmatised person is one who has lost their social identity and becomes discounted by others in the social world (Goffman, 1963 in Lillrank, 2003, p 12). Stigma can be associated with chronic pain where the patient fears they are being perceived by health professionals as someone without a valid or legitimate claim to their subjective experience of pain (Rhodes et al, 1999, Walker et al, 1999). This situation is most commonly associated with two related issues: 1. Failure of the pain to be objectively, biomedically validated i.e. no 'real' or biophysical cause has been identified to account for pain and 2. The inference that pain is 'in the mind', that the individual is weak or neurotic or mentally impaired (Seers and Friedli, 1996, Johansson et al, 1999; May et al, 2000). Those who have failed to have their pain validated as 'real' or fail to attain a defined medical diagnosis describe medical interactions as being anxious and conflict filled (Henriksson, 1995) and associated with a range of negative emotions e.g. frustration, mistrust, humiliation, shame and distress (Honkasalo, 2000; Kugelmann, 1999; Rhodes et al, 1999; Walker et al, 1999).

These accounts of non-legitimation and conflict are, notably, all from studies with samples with no medically defined cause of pain. Those with a 'disease' are able to explain their situation to others and give their experience an identity (Hilbert, 1984) and therefore establish their trustworthiness or credibility (Honkasalo, 2000). It is therefore likely that issues of challenged pain-legitimacy would be different for those with RA in comparison to those with non-defined conditions e.g. fibromyalgia (Johansson et al, 1999). It might then be assumed that those with RA would not produce accounts referring to justification of their pain as 'real' as their disease entity is strongly associated with pain medically and culturally (*Badley and Wood, 1979; Price et al, 1983*). However, the few studies reporting patients' understanding of pain in RA suggest that justifying or legitimising pain to others may be an issue in RA (Locker, 1983, Bury, 1988; *Wiener, 1975*). Accounts of living with RA refer to concerns about what are socially acceptable and unacceptable behaviours and fears that as levels of disability fluctuate day-to-day they may be seen as malingers or lack credibility and make attempts to conceal difficulties and act as 'normal' (Bury, 1988; Locker, 1983; Shaul, 1995; *Wiener, 1975*). This suggests that variable pain experiences may erode the individual's sense of credibility through consideration of other's evaluation. As the pain experience in RA may relate only moderately with clinical measures of disease activity and can be present without accompanying signs of active disease (e.g. swollen joints; Coster and Bengtsson, 2001; Hewlett et al, 1995) the legitimacy of pain could potentially be challenged in the clinical context. The lack of accounts of



challenged legitimacy of pain in RA may reflect it as a non-issue or the lack of in-depth study of clinical-contextual issues of pain in RA.

#### ***4.5.3.2 The role of medical imaging and diagnostics in legitimising pain***

The doctor is seen as responsible for the identification of the cause of pain experiences and diagnostics (Kugelman, 1999; May et al, 2000). Imaging tests and scans e.g. plain radiographs or magnetic resonance imaging (MRI) are seen by patients as important means to legitimise pain and hence provide a meaning for pain experiences, in ways that are irrefutable and are therefore common topics in pain accounts (Kugelman, 1999; Rhodes et al, 1999). Kugelman (1999) identified that patients felt an obligation or responsibility to try and have their private pain objectified and communicated to others, imaging forming an important part of medical verification. Those with severe osteoarthritis recognised the importance of radiographs to confirm their diagnosis, some suggesting that the objective tests could be used by the doctors to determine the degree of pain that would be anticipated, over-riding the patient's report (Sanders et al, 2002 and personal communication with the author, 2002).

The medical gaze, seeking to localise disease process and changed structure or function within the body and its systems, are a focus in medicine and correspondingly also for the lay person (Atkinson, 2002, p19-34). This is confirmed by the theme described in this section, where patients seek positive findings from objective measures and clinical tests and imaging to verify their pain as 'real'. Whether imaging or testing or assessment through examination is perceived as important in RA, as a means to vindicate patients' subjective experiences of pain, has not been explored within the literature.

#### ***4.5.3.3 Ascribing blame and responsibility for pain***

Blame is a recurrent theme regarding interactions with medical professionals and patients in a number of circumstances. Most commonly patients perceived that medical staff would shift blame to them or shift responsibility for treatment to other healthcare professionals when they were not seen to improve (Walker et al, 1999) or where there were no objective indicators for pain and the patient could stand accused of being the cause of the problem (Howell, 1994, Hilbert, 1984). Patients perceived that culpability or responsibility for the management of pain was negotiated based upon evaluation of its validity, the patient expectant that medical



sources will deal with pain of bodily origins, the doctor moving responsibility to others or back to the patient in the absence of objective indicators (Howell, 1994; Johansson et al, 1999; Osborn and Smith, 1998; Rhodes et al, 1999; Söderberg et al, 1999). This conflicts with patients' views of health professionals as being responsible for providing diagnosis, expert advice and knowledge, treatment and relief from pain (Bury, 1988; Howell, 1994; Kugelmann, 1999; Locker, 1983; Ryan et al, 2003b; Walker et al, 1999).

In contrast to the above, it is hinted in the accounts of patients' with chronically painful diseases that they *themselves* are responsible for their behaviour and obliged to get well or at least 'get on with life' in spite of pain and make the most of their own resources (Dickson and Kim, 2003; Sanders et al, 2002). Charmaz (1983, p169) identifies in those who are chronically ill, ideologies of the social and moral correctness of accepting personal responsibility for attempting to return to a 'normal' life, re-establishing valued roles and a sense of self in spite of illness. Accounts of patients assuming responsibility for their own pain management was not evident as the majority of studies included in the metasynthesis were focused upon the problematic issues of blame from the clinicians' perspective. Whether patients with RA would be more or less likely to assume responsibility for managing their pain is unknown. The chronicity and variability of pain in RA may make it like osteoarthritis (OA), an expected part of life and might not necessarily prompt help seeking but instead prompt an increased reliance upon self-management. This area requires further exploration.

#### **4.5.3.4 The 'work' of presenting pain at the clinic**

Pain does not become pain until it is described or declared to be such by the patient, therefore, communication of pain or pain reporting is a fundamental element of the pain phenomena, an inter-relational dimension of pain (Kugelmann, 1997; Sullivan, 1995 and 2001). Patients express frustration at not feeling they are able to fully convey their pain experience to others, e.g. doctors (Hellström, 2001, Hilbert, 1984; Walker et al, 1999), and patients are aware that pain is essentially private and there is no actual means to verify or correctly describe it (Hilbert, 1984). Within the clinical context, accounts of carefully balancing the presentation of pain problems to medical professionals were found, predominately where there was doubt about the biological basis of their pain (Werner and Malterud, 2003). Patients emphasised the coherence of their symptoms and minimised any possible link between psyche and soma, putting forward a pain report that aligned with a credible, biomedical and socially acceptable role (May et al, 2000; Werner and Malterud, 2003; Werner et al, 2004). Underpinning this theme is an

attempt to fit symptoms within the biomedical frame of reference, where the pain report is associated with valid degrees of disability and complaint, negotiating the balance between demands made and appearances, and expectations of their action (Werner and Malterud, 2003). Ultimately, attending to presentation of a socially credible self requires a credible pain i.e. not too healthy nor sick, presenting with 'real' bodily pain reports, minimising the inclusion of psychological explanations whilst not appearing to be too complaining (Werner and Malterud, 2003; Werner et al, 2004). Patients therefore appear to show understanding of what they perceive to be a competent consultation for a pain complaint, constructing their performance accordingly.

In general, 'illness-talk' is associated with the potential for the individual to be defined as a complainer or malingerer (Radley and Billig, 1996). Patients' decision to conceal or disclose pain may be influenced by socially mediated factors e.g. not wanting to be perceived as a complainer, repelling others (Hilbert, 1984; Johansson et al, 1996) or someone who has a negative effect upon 'social spirits' or not wanting to burden others or be the subject of sympathy (Hilbert, 1984, p371; Osborn and Smith, 1998; Paulson et al, 2002). The pain account in the clinic is likely to be most influenced by the presence of the judging doctor, an 'authorised moralist' within society (Nijhof, 1992, p10) and a key figure in evaluation of the patient and their pain. However few studies question how the medical world comes to influence patients, a criticism of much qualitative studies of chronic illness experiences (Thorne and Paterson, 1998).

Is this type of 'work' on perceptions related to pain reporting pertinent in RA? Patients with RA talk about balancing between concealment and disclosure of the severity of suffering to family, balancing wanting legitimisation and acknowledgement of pain against not wanting to create family disruption (Bury, 1988). Evidence of conflict about what to say and to whom to say it (*Williams and Wood, 1988*) suggests a degree of censoring of reports. In the clinical context the patient with RA appears to discriminate between what accounts are most appropriate for the rheumatology nurse i.e. expression of psychosocial concerns, and the rheumatologist i.e. primarily issues about their physical considerations, changes in status, expert knowledge of drugs and the disease (*Barlow et al, 2002; Ryan et al, 2003b*). This suggests differentiation of accounts of the consequences of living with RA. However, pain specific issues of clinical concealment/disclosure of pain are not found within the literature. The doctor is a key provider of education for the patient and the consultation is a place of implicit learning (Skelton, 1998). The failure to explore clinically oriented meanings of pain in RA, limits knowledge of

the intended as well as unintended effects of health professionals' practice in the clinical context and generation of clinically relevant findings.

#### 4.5.4 Summary of the Key Themes Identified

The metasynthesis of 24 studies of insiders' views on chronic pain generated multiple key themes, grouped into three types - shared meanings, consequences of pain and clinical-contextual meanings; these are presented in Tables 4.5.4a, 4.5.4b and 4.5.4c along with the gaps in existing knowledge.

**Table 4.5.4a Summary of the Key Themes and Gaps in the Literature Classified as Shared Meanings of Pain**

Shared Meanings of Pain Key Themes	Gaps in the Literature
Pain is understood to signify body malfunction or imbalance, integrate biomedical referents in accounts, corresponding to a reductionist biomedical view of pain.	Personal narratives about pain appear to be more complex than biomedical theories, influenced by peers, health professionals, context etc. Not clear how and what influence these have.
Physical pain i.e. related to biophysical origin is distinguished from mental pain, the former associated with greater kudos and legitimacy. Notions of mental pain resisted by those without a formal diagnosis.	Not known how those with RA make sense of their variable pain experiences.
	Is 'pain legitimacy' an issue for those with chronically painful conditions, like RA? No in-depth study of pain meaning in RA. Limited accounts suggest the 'reality' of pain can be questioned or challenged in RA by friends/family.

**Table 4.5.4b Summary of the Key Themes and Gaps in the Literature Classified as Consequences of Pain**

Consequences of Pain Key Themes	Gaps in the Literature
Pain associated with impaired performance and loss of valued activities	Similar accounts in RA but not specifically related to pain but whole illness experience i.e. impact of fatigue and pain not distinguished
Pain threatens integrity of self, a form of suffering.	Lack of work on how patient re-defines self (positive accounts)
Sub-themes:	Not enough detail in RA studies to comment upon the sub-themes found here
<ul style="list-style-type: none"> <li>• isolation</li> <li>• feeling discredited</li> <li>• living a restricted life</li> </ul>	Minor theme emerged in RA studies regarding intense pain and fear/helplessness, under explored area
Minor theme (only in defined conditions): acceptance and tolerance of pain associated with ageing	Suggestion of tolerance of pain in RA with time, under-explored

**Table 4.5.4c Summary of the Key Themes and Gaps in the Literature Classified as Clinical-Contextual Meanings of Pain**

Clinical-Contextual Meanings of Pain Key Themes	Gaps in the Literature
Doctor is vital in legitimising pain via diagnostic label and identifying pain as 'real' or of organic basis	Not explored in RA suggested that patients perceive some doctors not take symptoms seriously Is legitimacy of pain an issue in RA clinically?
Stigma associated with non-legitimation e.g. fraud, malingerer	
Legitimising pain via diagnostic testing and imaging - strong verification of pain reality	Not examined in RA, suggestion that clinical tests highly valued but whether it challenges pain experience is not known
Doctors shifting blame for pain and distress and responsibility to others or patient when it is not validated as 'real'	Suggestion in other defined conditions that patients may assume self responsibility Not explored in RA. What is the doctor responsible for? For what is the patient responsible?
Patient considers the 'audience' i.e. the doctor when presenting the pain report, works to present pain in a credible way	Social undesirability of pain reports may play part in pain concealment Suggestion that RA patients differentiate accounts of pain depending upon audience Not explored regarding clinical context

## 4.6 CRITIQUE OF THE METASYNTHESIS STUDIES

Studies included within the metasynthesis were critiqued as a whole body to highlight strengths and weakness of the field through analysis and interpretation of theoretical perspectives assumed, methodological applications and the nature of analysis and findings (Finfgeld, 2003).

### 4.6.1 Failure to Integrate Knowledge from Diverse Fields

The orientation of study findings is strongly shaped by the theoretical underpinning of the study via framing research questions, data collection methods and interpretation of the findings. Psychologically orientated studies explored the cognitive and interpretive efforts of the patient (e.g. Hellström, 2001; Osborn and Smith, 1998), sociological inquiry considered the social and cultural norms and values that shape illness (e.g. Hilbert, 1984) and those with an applied health science orientation gravitated towards how the study could inform clinical practice (e.g. Walker et al, 1999). Researchers from varied disciplines (e.g. health sciences - Walker et al, 1999; psychology - Hellström and Carlsson, 1996; nursing - Thomas, 2000) appeared to fail to integrate or acknowledge work that was relevant to their area of inquiry, particularly work from the sociological field (e.g. Hilbert, 1984; Howell, 1994). Walker et al (1999, p621) states: 'Little attention, beyond anecdotal discourse, has been given to the lived experience of people with back pain', overlooking other qualitative studies of chronic low back pain (e.g. Borkan et al, 1995; Nijhof, 1992; Osborn and Smith, 1998).

An overall survey of chronic pain literature emphasises the significant impact of social and moral factors in shaping the illness experience in chronic pain e.g. changing roles, relationships (Kleinman, 1988, p170-185; Kugelman, 1999), patients' concerns about how they present themselves in the clinical context (Werner and Malterud, 2003; Werner et al, 2004). However, these social dimensions have witnessed little exploration from health science orientated researchers who have mainly concentrated upon describing the disruption to life that pain causes (Osborn and Smith, 1998; Seers and Friedli, 1996; Söderberg et al, 1999; Walker et al, 1999). These studies were orientated to the clinical world and the patient with pain, potentially offering the most clinically applicable findings. However, by failing to acknowledge and integrate social explanations to explain and frame their analysis they failed to generate wider explanations for their observations.

It is as if there were a language barrier based upon epistemological stance, researchers perpetuate serialisation of phenomenological explorations, returning to patients' general experiences of living with chronic pain by suggesting the area is under-explored (Henriksson, 1995, Johansson et al, 1999; Seers and Friedli, 1996, Söderberg et al, 1999; Thomas, 2000). Themes generated are conspicuously familiar as they are already well documented and discussed within sociological literature on chronic illnesses e.g. themes related to being discredited (Charmaz, 1983; Corbin and Strauss, 1987). Studies have therefore failed to build upon existing concepts and themes. This limits evolution of the body of knowledge, leaving it stuck at the level of theme description, and presenting as a barrier to generating explanation and theory. Studies would benefit from adopting more encompassing paradigms, a paradigm of choices that would enable a more inclusive approach to study design and interpretation anticipating that social and cultural resources, inter-personal relations and moral issues will be present (if looked for) in patients' accounts of chronic pain.

#### **4.6.2 Focus Upon the Negative Conceptions of Pain**

A key feature of the studies reviewed is the persistent presentation of negative views or themes related to pain. Contrary to this, findings from studies of patients with chronic illnesses (e.g. cardiovascular disease) are more balanced, suggesting that 'transcendence' (Corbin and Strauss, 1987, p271) or finding new meaning through illness can be achieved, a source of self development (Charmaz, 1983). This negative orientation may correspond to the sampled groups, persistently selecting convenience samples from pain clinics or pain management programmes. Patients with chronic pain who do not have a defined diagnosis are more distressed and report greater pain than those with a defined condition (Geisser and Roth, 1998). The researcher who approaches them at a pain clinic may give a route for patients to air a complaint (Kugelman, 2002) or present their legitimate claim to medical attention (May et al, 2000). This may also be a product of researchers' aims, to find out 'what goes wrong' rather than exploring and building upon previous work revealing successful and positive lives through and with chronic pain (e.g. Howell, 1994). Overall there is a bias towards an exposure of problems and suffering, mirroring what already exists rather than attending to what patients are actually saying.

### 4.6.3 Sampling Composition

There is an obvious selection bias in this type of research to study those who have un-explained chronic pain, which has no identifiable biological cause or disease basis and is not expected to respond to biomedical treatment. The orientation to insiders' views on chronic pain appear to be following a common ground of emphasis upon the problematic nature of pain, negative consequences for life and self and the patient who presents as medically difficult to manage (May et al, 2000; Osborn and Smith, 1998) and thus requires treatment at specialist pain clinics (Hellström and Carlsson, 1996; Honkasalo, 2000; Johansson et al, 1999; Kugelmann, 1999; Osborn and Smith, 1998; Seers and Friedli, 1996; Söderberg et al, 1999). It is likely that these patients will have a particular view of pain related to the nature of their medical interactions and failed attempts to find and receive a diagnosis and effective pain relief (Hellström, 2000; Osborn and Smith, 1998). Chronic or medically unexplained conditions challenge doctors (Sullivan, 2001). The patients with unexplained physical symptoms causing 'heart-sink' among the medical professions (O'Dowd, 1988 in Salmon and Hall, 2003) are therefore likely to generate a specific type of interaction and reaction and pain account.

The propagation of studies about this patient group is arguably at the expense of investigating other conditions (with a few exceptions of studies of osteoarthritis - Dickson and Kim, 2003; Sanders et al, 2002). Lack of in-depth study of pain in chronically painful diseases infers that pain is not a problematic issue for the medical world dealing with RA, despite patients accounts that suggest the contrary (Bury, 1988; Heiberg and Kvien, 2002; Minnock et al, 2003; Ryan et al, 2003b). Sanders et al's (2003 and 2004) studies of OA suggested that where elderly patients perceived their severely painful joints to be a normal part of living with OA they failed to utilise relevant healthcare services. Whether similar issues exist in RA are not known.

As previously mentioned, RA studies are few and half of those found were dated (Locker, 1983; Bury, 1988). Locker's study (1983) sampled only those with severe disability and Bury's (1988) only sampled those who were newly diagnosed, with a preponderance of young patients (19 of 25 being under 54 years old). Ryan et al's (2003b) report is short with limited description of pain issues. Shaul's USA-based study (1995 and 1997) sampled only females. Further criticism is that in three of these studies no attempts were made to vary the sample representation regarding class, employment or educational level (Bury, 1988; Locker, 1983, Ryan et al, 2003b). It is known that in RA variation of socio-economic status influences disease outcomes and illness experiences (Hamilton et al, 2001 McEntegart et al, 1997; Mitchell et al, 1988).



#### 4.6.4 The Quality of the Qualitative Studies

Whether constructs of validity, reliability and objectivity are considered as desirable or achievable in qualitative interpretive research inquiry depends upon the theoretical position of the researcher (Grbich, 1999). However, irrespective of the researcher's position there has to be some accounting for the truth value of the interpretations made and the researcher must convince the reader that the study accurately represents the phenomena being studied (Mason, 1996). This area of critique provided the greatest substance for discussion. In a significant number of studies there was no reference to, or acknowledgement of, issues of validity or any other derivative representative of a rigorous approach to qualitative researching (Hilbert, 1984; Honkasalo, 2000; May et al, 2000; Thomas, 2000). Others presented a few references suggesting an awareness that the author should attempt to show how they may have shaped the findings and justify the comprehensiveness of their exploration or the scope of their inquiry (e.g. Rhodes et al, 1999; Ryan et al, 2003b; Walker et al, 1999). Only three examples presented a clear acknowledgement of the necessity to present the reader with a means to judge the quality of their work and interpretation (Hellström, 2001; Howell, 1994; Sanders et al, 2002). The lack of reference to the potential influence of the researcher upon the findings generated was the most consistent omission and relates to nearly all studies with few exceptions (exceptions - Hellström, 2001; Osborn and Smith, 1998). The absence of reference to issues of credibility and truth value in studies may be related to the constraints on word count for journal articles or the researchers' philosophical position, however, omission leaves the reader unable to assess the value of the findings and leaves them open to criticism.

How thoroughly or completely a phenomenon was explored was another indeterminable element within the studies critiqued. There was little documentation of attempts to search for negative cases or those accounts that did not 'fit' a particular theme. Neither was there articulation that a theme or category was fully described or defined or, alternatively, incompletely understood (May et al, 2000; Thomas, 2000; Werner and Malterud, 2003). The brevity in descriptors of analysis meant that the reader could not account fully for what was actually done in the studies surveyed, particularly with regard to processing of the findings (exceptions to this were - Hellström, 2001; Howell, 1994, Sanders et al, 2002). Brief statements regarding the process of analysis in three or four lines was common with no indication of how they came to identify key themes and inter-relations (with the exception of; Dickson and Kim, 2003; Hellström, 2001; Howell, 1994; Sanders et al, 2002).



#### 4.6.5 Limitations in the Analysis of Findings

Sandelowski and Barroso's (2003) typology of qualitative findings was used to classify and differentiate between the varied sets of findings reviewed. This typology was developed in recognition of the fact that despite variations in theoretical viewpoint, and the researchers' proposed methods, qualitative research findings are presented in a uniform way, allowing classification (see Table 4.6.5). This classification enables critical review of what was actually done in a study rather than what they said they would do, two facets which often fail to accord (Sandelowski and Barroso's, 2003; Thorne et al, 2002).

**Table 4.6.5 A Typology of Qualitative Findings (primary reference: Sandelowski and Barroso, 2003)**

Type of study finding	Features/defining characteristics	Level of interpretation
No finding	<ul style="list-style-type: none"> <li>Where data is presented as if it were a finding e.g. reproducing a case description or history.</li> <li>Not research.</li> </ul>	Minimal or no attempt at judging or interpretation of the data.
Topical survey	<ul style="list-style-type: none"> <li>Listing or grouping the topics covered by participants, manifest content analysis with summarisation of key features.</li> <li>Organisation of topics using classification systems adopted a priori.</li> <li>Not qualitative research (although using qualitative methods).</li> </ul>	Minimal interpretive effort only classifying and categorising.
Thematic survey	<ul style="list-style-type: none"> <li>An interpretive product with emphasis upon qualifying a theme, removed from participants' language.</li> <li>Exploratory research</li> </ul>	Transform data from manifest level to latent level.
Conceptual or thematic description	<ul style="list-style-type: none"> <li>Parts of the data are interpretatively re-integrated, removed from the manifest level or respondents' language.</li> <li>Re-framing the phenomenon.</li> <li>Extend theoretical or knowledge base.</li> <li>Descriptive, qualitative research</li> </ul>	Data transformed and re-integrated.
Interpretive explanation or theory	<ul style="list-style-type: none"> <li>Producing a theory or integrated explanation to account for the experience or phenomenon.</li> <li>A coherent model is produced or a single line of argument that addresses the essence of the phenomenon.</li> <li>Explanatory qualitative research</li> </ul>	Data transformed and re-integrated in a new way.

The methodological approach for nearly half the studies examined was not specified but it was implied through study design and methods to be generic, qualitative-interpretive study. The rest were predominately interpretive phenomenological. Irrespective of the stated methodological orientations most proceeded with account gathering

via individual, one-off, semi-structured interviews which were then processed to a stage of identifying themes or categories. Most limited the processing of findings to the level of thematic description of the phenomenon of pain i.e. without significant interpretive effort. Those studies with a clinical orientation e.g. exploring patients' conceptions of the medical world with which they interacted (Walker et al, 1999) most often stopped processing findings at the level of surveying (May et al, 2000; Seers and Friedli, 1996; Walker et al, 1999). The listing of topics mentioned by respondents was presented in a language close to that of the patients, with minimal interpretive processing. Working from the basis that patients' concerns and views are key, and adopting descriptive, qualitative approaches, most studies showed little progression in their analysis from the simple descriptive level. By stating the theme without recourse to integrating others' findings or inter-relating themes to show connections (e.g. Walker et al, 1999) many researchers presented a survey-type list of the key themes and did not endeavour to integrate established social theories e.g. ideas about moral order when sick (Kotarba, 1983). They were, therefore, unable to move from the contextual observations to the wider social and cultural influences that are known to shape these types of findings.

Notably, the pain related findings from the RA specific studies are minimally abstracted (Bury, 1988; Locker, 1983; Ryan et al, 2003b). Locker (1983) presents elaborate description similar to Bury's (1988) topical survey type findings. Ryan et al's (2003b) study report is limited in size which may account for the presentation of thematic survey-type findings and the lack of integration and exploration of why the accounts denoted were found. Shaul (1995 and 1997) moved to thematic description but failed to show how themes may change with time and experiences presenting an unconvincing linear construct of patients moving from early symptoms of RA to 'mastery'. Overall, studies failed to reveal the complexity of patients' accounts, there being no sense of the findings being rich, informative, contradictory or unexpected. This resulted in a loss of the complexity of contextual meanings and a failure to combine and integrate with higher levels of abstraction. The result is an oversimplification of complex experiences and situations, presented as a group of descriptive themes.

In comparison, data processed to the level of theory (Howell, 1994) or founded upon integrated themes provide the basis for explanation and potential direction for intervention or subsequent quantitative investigation (Dickson and Kim, 2003, Sanders et al, 2002). These comprehensive and insightful works typically integrated social theories or experiential processes as well as others' work to provide greater understanding of the phenomena. The data was questioned beyond, 'what do patients say', to 'why do patients say that and what are

the processes or explanations for what was found in the accounts and what purpose does it serve?' Those studies that were non-clinically orientated but integrated socio-cultural explanations did not have sufficient detail of the clinical encounter or medical interactions capable of exposing how these may shape pain meanings (Hilbert, 1984; Sanders et al, 2002).

#### **4.7 SUMMARY AND CONCLUSIONS**

Studies of pain accounts from the patients' perspective (insiders' views of pain) irrespective of the label assigned to the individual (fibromyalgia or RA) highlights the complexity of pain accounts and the variety of dynamic meanings generated. Pain meanings reflected explanations of the cause of pain, consequences or lived experiences of pain as well as those meanings specific to medical management/interactions. Strongly evident in insider themes was the significant influence of the medical-scientific world i.e. biomedical explanations and interactions with doctors shaping pain meanings. Key themes identified were significantly more developed for samples without formal diagnoses in comparison to chronically painful diseases and focused upon problematic issues rather than positive adjustment to life with chronic pain. Studies of RA were poorly represented, with dated studies, which were further limited by sample composition and the underdevelopment of themes in all areas due to the lack of in-depth reporting of pain issues. Overall, studies commonly failed to build on existing knowledge located in fields outwith researchers' familiar domains. This constrained interpretive efforts (which often stopped at the level of description) and failed to explore the inter-relationship of themes or to elucidate ways in which different processes e.g. context, shaped the meanings presented, thus, ultimately limiting the usefulness of the work. These findings support the need for an in-depth, interpretive-qualitative study of pain meanings in RA that attends to the multiple meanings of pain and processes/influences that may shape these. The study should build upon existing work and examine pain accounts from patients who are likely to have diverse pain experiences. Particular attention should be paid to clinical-contextual meanings as patients' views of 'pain' (undifferentiated) appear discordant with the current medical understanding of 'chronic pain' which is, in turn, associated with problematic patient-doctor interactions. These issues are relevant to patients and doctors who meet at the clinic to make sense of pain and its management.

## **5 CHAPTER FIVE - RHEUMATOLOGISTS' PERSPECTIVES ON PAIN IN RHEUMATOID ARTHRITIS**

### **5.1 INTRODUCTION**

The scientific world and medical ways of thinking about pain strongly influence western society's conceptions of pain. Medicine can be viewed as a sub-culture itself, having its own language and practice and ways of understanding pain (Davis, 1998; Eccleston et al, 1997). These ways of knowing about pain can be represented by various models and influence health professionals' understanding and response to pain (Hanson and Gerber, 1990). Two key models of pain are described before presenting a critique of the literature regarding doctors' representations of chronic pain. This provides support for this study's sampling strategy and identifies gaps in the existing literature. A small number of studies (n=12) were found exploring doctors' chronic pain conceptions. In the absence of any studies relating to pain in RA or rheumatologists' pain perspectives an overview of the pain discourse in rheumatological texts is presented. The chapter concludes by suggesting a range of factors that may add to the complexities of conceptualisations of pain in the clinical setting e.g. resources. It is argued that previous research has failed to address such issues and that exploration is required of not only of *what* rheumatologists understand of pain and its management in RA but also of *how* they use pain knowledge in practice; these questions are addressed by this study.

### **5.2 THE BIOMEDICAL AND BIOPSYCHOSOCIAL MODELS OF PAIN**

How an individual makes sense of their own and others pain and how they determine responses to pain can be understood in terms of models of pain (Hanson and Gerber, 1990). A model can be described as a conceptual framework and provides a succinct description of processes or systems (Young and Quinn, 1992). The biomedical and biopsychosocial models are the two dominant pain models identified within current pain literature (Clark and Cox, 2002). These may shape the ways that individuals, and particularly health professionals, think about pain (Main and Spanswick, 2000) and therefore would be expected to permeate doctors' accounts of pain.

### **5.2.1 The Biomedical Model of Pain**

The biomedical view categorises pain as an aversive sensation, directly indicating injury or pathology affecting body tissues i.e. pain is a symptom of underlying tissue damage (Armstrong, 1995). This framework reflects notions of the dualistic separation of mind and body, where 'real' pain is supported by objective physical/somatic findings, versus pain reports in the absence of confirmatory evidence within the body, which is classified as 'functional' or psychogenic pain (Sullivan, 2001). The approach to pain treatment is reductionist, identifying and directing treatment to the periphery or to stop/slow disease processes i.e. directing treatment at the body rather than the person (Hanson and Gerber, 1990). The biomedical approach to pain is criticised for reducing pain to a sensation and a medical problem rather than a personal experience integrated with the individual's thoughts and feelings, shaped by social and cultural factors (Bendelow and Williams, 1995).

### **5.2.2 The Biopsychosocial Model of Pain**

Current theory advances pain as a multi-dimensional phenomenon, a product of complex, interactive processes modulated by multi-dimensional systems (Kugelmann, 1997). Complementary to advances in the field of pain theory, the biopsychosocial model of pain is promoted as the most appropriate approach to help understand pain and is also used as a guide for treatment interventions (Keefe and Bonk, 1999). Based upon Engel's paper (1977) this model provides a systems perspective on pain, where phenomena are understood by examining the interactions between multiple elements. Less reductionist than the biomedical model, the biopsychosocial model allows for incorporation of a range and diversity of mediators of pain. It integrates the bi-directional and dynamic nature of pain as it produces biological, psychological and social changes that, in turn, can influence pain and pain responses (Keefe and France, 1999). This model has been promoted as especially relevant for the care of patients with RA, whose pain is chronic and correspondingly multi-dimensional in nature (Simon et al, 2002). Table 5.2.2 presents a summary of the main features of each model of pain. Despite the progression of understanding about the complexity of the pain phenomenon it is suggested that doctors still attempt to identify a cause of pain located somewhere within the body (Priel et al, 1991; Sullivan, 2001). In an overview of pain, Loeser and Melzack (1999, p3) suggest that: 'Many physicians and patients do not realise pain can occur without nociception'.

**Table 5.2.2 Contrasting the Key Features of the Biomedical and Biopsychosocial Models of Pain (adapted from Hanson and Gerber, 1990, p30)**

Biomedical Model	Biopsychosocial Model
Emphasises peripheral nociceptive mechanisms of pain	Integrates the role of central and peripheral mechanisms in modulating the pain experience, encompasses circumstances where pain can be experienced in the absence of nociception
Focuses upon physical disease mechanisms	Integrates concepts of illness behaviour, learning and socialisation in shaping the pain experience, which includes sensory, emotional and cognitive dimensions
Reductionist approach to understanding and treating pain	A multidimensional, systems approach to understanding and treating pain and its consequences
Reliance on medical approaches to pain management e.g. pharmacological treatment of the disease	A multidimensional and multidisciplinary approach to pain management e.g. patient education, self-management training etc

### 5.3 A LITERATURE REVIEW OF DOCTORS' PERSPECTIVES ON CHRONIC PAIN

To examine the literature relating to doctors'/physicians' perspectives on chronic pain and pain in RA, searches were performed using several electronic databases: MEDLINE, the Cumulative Index of Nursing and Allied Health (CINAHL), PsychLIT and the Social Sciences Citation Index (SSCI). Searches were conducted for studies published in English during the period - 1990 to 2004. Citations were searched for any key texts published before 1990 (see Appendix 6.1 for the search-terms used). Twelve studies were identified as being relevant to this study (see Table 5.3). Seven studies were conducted in the USA, two in Scandinavian countries and one in each of the UK, The Netherlands and France. Notably, five of the studies relate specifically to chronic low back pain and four refer to pain specialists' views. Only one study, whose findings were reported in two articles, addressed doctors' perspectives on chronic pain in cases where there were varied causes e.g. RA, cancer etc. (Green et al, 2002 and 2003). Several key issues were identified from the literature:

- the limited number of studies and the diversity of study orientations;
- methodological and measurement issues; and
- limited study populations and limited reference to pain in chronic diseases.

**Table 5.3 Key Literature Regarding Doctors' and Student Doctors' Perspectives on Chronic Pain**

Author Location of study	Sample Group	Pain Type	Study Topics and Methods
Baszanger (1992) France	Chronic pain specialists	Chronic pain	Contrasting two pain centre approaches; observation, interviews
Cherkin et al (1985) USA	Physicians from mixed specialities	Acute and chronic back pain	Beliefs regarding treatment efficacy; survey methods, vignettes
Chibnall et al (1997) USA	Medical students	Chronic low back pain	Factors influencing judgement of pain; vignettes
Eccleston et al (1997) UK	Health professionals (including medical pain specialists)	Chronic pain	Understanding of the cause of pain; Q-methodology (Corr, 2001)
Green et al (2002 and 2003) USA	GPs and hospital specialists	Chronic pain	Knowledge and management of pain; survey methods, vignettes
Paulson et al (1999) Sweden	Nurses and physicians	Chronic pain in men	Doctors' perspectives on patients' pain experiences; qualitative interviews
Mäntyselkä et al (2001) Finland	GPs	Non-chronic and chronic pain	Comparison of patients' and GPs' pain ratings; use of Visual Analogue Scales
Rainville et al (1995) USA	Varied health professionals and physicians	Chronic low back pain	Attitudes and beliefs regarding function and impairment; questionnaire
Rainville et al (2000) USA	GPs and hospital-based specialists	Chronic low back pain	As above and recommendations for activities; questionnaire, vignettes
Tait and Chibnall (1997) USA	Physicians	Chronic low back pain	Factors influencing judgement of pain; vignettes
Vrancken (1989) The Netherlands	Chronic pain specialists	Chronic pain	Comparison of approaches at eight pain centres; observation, interviews
Wilson et al (1992) USA	Medical students	Acute and chronic pain	Attitudes towards pain; questionnaires



### **5.3.1 Limited Study Numbers and Diverse Study Orientations**

In comparison to the number of studies exploring health professionals' perceptions of acute and cancer pain there are few studies relating to doctors' perspectives on chronic pain (Rich, 2003). To compound this, of the few studies found, a range of different study perspectives are adopted (see the right-hand column of Table 5.3). For example Wilson et al's (1992) study surveyed the changing attitudes of medical students before and after a pain course using an 8-item questionnaire, attempting to address issues related to both acute and chronic pain. Other studies used specially designed questionnaires to address beliefs related only to chronic back pain disability (Cherkin et al, 1985; Rainville et al, 1995 and 2000). The other main research orientation is to investigate the influence of patient factors (e.g. self-reported pain intensity; Chibnall et al, 1997; Tait and Chibnall, 1997) or doctors' characteristics (e.g. age; Green et al, 2002) upon clinicians' decision-making. This varied work has resulted in a little being known about a range of issues regarding chronic pain, failing to build knowledge in any particular area; with most being known about chronic low back pain. Few have approached the area by broadly exploring the multiple dimensions of doctors' pain meanings e.g. pain mechanisms, management goals, expectations, treatment views etc. Notably, the exceptions to this (i.e. Baszanger, 1992; Vrancken, 1989) are dated studies and pain management has advanced over the past 15 years (Chapman et al, 2001). In addition, these two studies relate only to pain specialists' views on chronic pain. This constrains the generalisability of the findings to other medical professionals as studies suggest that a professional's speciality influences their pain perspectives (Jones et al, 2001; Rainville et al, 1995 and 2000). There were no studies found which exclusively explored rheumatologists' pain perceptions.

### **5.3.2 Methodological and Measurement Issues**

To quantify the relations between patient presentation variables and/or doctors' demographics and how they influence doctors' pain management decisions, most studies used questionnaires or vignettes. Using the latter method has enabled researchers to present 'paper-patient' details to doctors whilst modifying variables of interest (e.g. pain intensity or medical information) and establish the outcome of these modifications regarding doctors' pain evaluations (Chibnall et al, 1997; Green et al, 2002 and 2003; Tait and Chibnall, 1997). Although the use of vignettes give insight into how doctors may apply knowledge and make decisions (Jones et al, 1990) they can be criticised for presenting a relatively simplistic and limited set of information that is devoid of the complexities of patient-doctor encounters (Tait and Chibnall, 1997). The use of validated questionnaires and researcher-designed



surveys has enabled researchers to collect data from large numbers of physicians (Green et al, 2002 and 2003; Rainville et al, 1995 and 2000). However, examination of these tools suggest a trade-off between attempts to contain the size of these tools, to encourage a good response rate, and compromising the number of questions posed, which are necessary to address doctors' understanding of the multiple dimensions of pain. The pre-defined structure and content of the questions, and given responses, fail to address 'why' the doctors give the responses they do. They also fail to aid understanding of whether some factors are more important than others in decision making or whether some variables have not been accounted for.

### **5.3.3 Studies Exploring Doctors' Diverse Pain Perspectives**

Only one study explored how doctors' perceived patients' experiences of living with chronic pain. Paulson et al's (1999) study of Swedish nurses' (n=17) and physicians' (n=4) narratives about men living with chronic pain identified several themes common to both groups. Respondents identified that men living with chronic pain (of undefined origin) were likely to withhold emotions or feelings about pain and focus upon the physical symptoms (i.e. not relating pain to non-somatic events). Doctors also identified that patients may experience a sense of lost self-identity associated with altered function, and their need for support and confirmation of their suffering from health professionals. This work is important in illustrating doctors' cognisance of some of the dimensions of patients' experiences, which also concur with patients' accounts (May et al, 2000; Seers and Friedli, 1996). However, the study is limited in its relevance to pain conceptions in RA as respondents were limited to talking about pain that had no identifiable organic cause which is known to influence patients' experiences (Werner and Malterud, 2003) and doctors' pain evaluations (Tait and Chibnall, 1997; Sharpe et al, 1994). Although it was documented that nurses and doctors did not all identify the same sub-themes there was no explanation or discussion as to why this may have been the case. The study also lacked mention of any procedures to support the credibility of the researchers' interpretation of the narratives, which leaves the reader unable to fully assess the validity of the findings.

Both Vrancken (1989) and Baszanger (1992) used qualitative-interpretive, field research approaches at centres specialising in the treatment of chronic pain. Each studied pain specialists' interactions with patients (through observation) and used interviews to develop in-depth understanding and explanation of how pain was

conceptualised. Vrancken (1989) studied eight academic pain centres in The Netherlands and found multiple perspectives among this group. Five major ways of conceptualising chronic pain were identified, see Table 5.3.3.

**Table 5.3.3 Approaches to Chronic Pain Described by Vrancken (adapted from Vrancken, 1989, p435-443)**

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Conceptualisation of Pain

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- **Somato-technical Approach**

An approach based upon a neuro-physiological model of pain, where pain is assumed to have an organic basis and the difference between acute and chronic is time. Pain patients grouped into three types: 'real' pain patient, psychiatric pain and malingerers. Treatment involved surgery or medications. Resolution occurs when objective signs are abolished.

- **Dualistic, Body-oriented Approach**

Pain is approached as a psychobiologic phenomenon i.e. the result of organic, psychological and possibly social factors, although physiological pathology is a necessary, major determinant. The 'dualistic' dimension is related to the dichotomy, which exists in practice, through classification of patients as chronic benign, chronic malignant or chronic pain syndrome. Treatment is dependent upon assessment of components and success is when pain is abolished.

- **Behaviourist Approach**

Chronic pain is viewed as a learned behaviour, a separate entity from nociceptive stimulus; largely due to behavioural changes, which are resultant from environmental factors. The psychologist is key in treatment with an aim to minimise pain behaviours ideally resultant in effective, adaptive behaviours.

- **Phenomenological Approach**

Pain is a complex interaction of reactions/behaviours, which may be triggered by harmful conditions. Pain as a 'mode of being' in which the body has come to the foreground or the centre of life for the sufferer, closely linked to disruption of social relations and isolation. Therapy is successful when the patient can re-emerge as a united and independent 'self'.

- **Consciousness Approach**

Pain as a problem of consciousness and relates to the body becoming part of the 'here-and-now' consciousness and the influence this may have upon awareness. Pain is part of what it is to be human. Pain can be seen as a condition that is limiting but need not determine self. The route to stopping pain is an act of will, to gain insight to accept or manage pain via varied therapies.

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Other work suggests that pain specialists' orientations towards pain in the UK may not be as diverse as found in Vrancken's study (Eccleston et al, 1997). However, these studies demonstrated that using a qualitative-interpretive approach, which asked doctors to explain what they were doing clinically and why, enabled the researchers to construct a framework of inter-linking pain perspectives. Vrancken (1989) was able to suggest which pain theories underpinned doctors' views and how these were related to classification of patients' problems, ideas about management as well as expectations of outcome. Although Vrancken's (1989) study can be strongly criticised for failing to provide supporting quotations or evidence of processes supporting

methodological rigour, the methodology did generate an in-depth description and explanation not seen in the quantitative studies. This level of explanation enabled Vrancken to suggest the influences which had shaped the doctors' views e.g. behavioural theories and/or the philosophy of the centre at which the doctor worked etc.

Baszanger's (1992) study of pain specialists' accounts advances understanding of the clinical dimensions of doctors' pain work. Baszanger reported that it appeared possible for clinicians to hold the same basic theoretical reference points (i.e. gate-control theory) but in practice apply the theory in different ways. The 'operational' model of chronic pain (i.e. the model used by clinicians to guide medical practices) was found to fulfil important social functions i.e. to justify the doctors' actions or to confirm/realign the patient-doctor contract or agreement. Baszanger's (1992) findings match with others' suggestions that when exploring a phenomenon (e.g. pain) it is necessary to explore not only what the professional knows or believes but also 'how' they explain their clinical practices (Berg, 1992; Jones et al, 2004; May et al, 2004). This may illuminate the complexities, conflicts and/or compromises evident in the clinical context (Jones et al, 2004). These findings suggest that the nature and circumstances of clinical pain work should be explored in any study that aims to understand what and how rheumatologists' conceive of pain in RA. Questioning the professional about patient-case examples and/or working practices may generate this kind of account.

#### **5.3.4 Limited Study Populations and Reference to Pain in Chronic Diseases**

Studies of health professionals' (e.g. nurses, therapists) pain knowledge, beliefs and attitudes with respect to acute and chronic pain suggest that different health professional groups have different pain perceptions (Eccleston et al, 1997; Jones et al, 2001; Rainville et al, 1995). Green et al's (2002 and 2003) study of GPs and hospital doctors also suggest that a doctor's speciality e.g. surgery versus general practice, influences their responses regarding pain management. In addition, health professionals' clinical experiences may shape their pain conceptions (Askew et al, 1998; Lebovits et al, 1997). Together, these present a case against generalising pain conceptions from one medical speciality to another. The absence of any studies of rheumatologists is probably a reflection of the under-developed state of research regarding doctors' pain perceptions.

Green et al's (2002 and 2003) study is unique in its presentation of vignettes with varied causes of chronic pain to doctors (e.g. rheumatoid arthritis, degenerative low back pain etc). They found that knowledge of pain treatments

and treatment goals varied for different chronically painful conditions. A study of nurses' intentions to manage pain for a range of hypothetical patient-cases, all with the same degree of pain, found variations related to the cause of pain e.g. cancer pain versus pain associated with drug abuse (Brockopp et al, 2003). Others have found that doctors and medical students tend to discredit patients' pain reports when there is an absence of supporting objective medical evidence or when pain is reported to be severe (Chibnall et al, 1997; Mäntyselkä et al, 2001; Tait and Chibnall, 1997). Although these different types of findings are likely to be underpinned by multiple factors, taken together they all suggest that it is likely that knowledge and/or evidence of a *specific cause* of pain will influence how pain and pain management is perceived by healthcare professionals. The majority of studies relating to doctors' pain perspectives focused upon undefined or non-disease related chronic pain (n=10). The management of pain in conditions like RA has to be balanced with treatment of the disease, complications and concurrent illnesses (March and Lapsley, 2001) and may influence how pain and pain management is perceived. This strengthens the case for a study focusing upon rheumatologists' perspectives on the management of pain in RA.

### **5.3.5 Key Findings Relevant to this Study's Sampling Strategy**

Despite the limited number of studies identified and their methodological weaknesses, some findings are consistent with studies of other health professionals' knowledge, beliefs and attitudes regarding pain and can inform this study's sampling strategy. It is suggested that health professionals' pain perspectives may vary in relation to age (de Rond et al, 2000; Green et al, 2002), gender (Weisse, 2004), length of experience (Askew et al, 1998), hospital location and/or institution type (Baszanger, 1992; Lebovits et al, 1997; Vrancken, 1989), and the types of patients seen (Marteau and Baum, 1984; Rainville et al, 2000; Törnkvist et al, 1998). It is also suggested that personal experiences of pain may influence pain beliefs (Haldorsen et al, 1996). To generate and fully explore a diversity of pain meanings with rheumatologists' these factors must be integrated within the study's sampling strategy and in the collection of demographic details.

## **5.4 PAIN DISCOURSE IN MEDICAL AND CLINICAL TEXTS ON RA**

A 'discourse' can be described as something which, 'provides a set of possible statements about a given area, and organises and gives structure to the manner in which a particular topic, object, process is to be talked about'

(Kress, 1985 cited in Price and Cheek, 1996, p212). By examining pain-related language in medical texts and clinical articles an impression of the likely nature of rheumatologists' discourse on pain can be collated.

#### **5.4.1 The 'Real' Pain of RA versus the Pain of Fibromyalgia**

It is suggested that the biomedical model serves as the basis for most doctors' training and practice (Ramos-Remus et al, 2000) a position increasingly challenged by chronic illnesses that require long-term management and working in partnership with patients (Callahan and Pincus, 1997). The biopsychosocial systems approach is promoted as an ideal model for care in chronic illnesses (Keefe and Bonk, 1999; Simon et al, 2002), however, the medical discourse on pain in RA suggests that pain is primarily viewed in a narrow, biomedical way (Dessein et al, 2000). The role of personal meanings and social factors shaping the pain experiences are not entirely discounted; instead, it is implied that, in RA, there is a proportional relationship between disease activity, physiological processes, joint damage and pain perception (Rice and Pisetsky, 1999). This is contradictory to those studies which report that the relationship between pain, impairment and disease processes in RA are neither simple nor directly proportional and that psychosocial factors play a significant part in modulation of pain in RA (Flor and Turk, 1988, Smedstad et al, 1995; Coster and Bengtsson, 2001).

The quotation selected from the introductory passages of the special edition of the Rheumatic Disease Clinics of North America (February, 1999), dedicated to pain in rheumatology, is used to illustrate the relatively minor role that non-biological factors are presented as having in shaping the pain experience in RA. The contrast between the medical approach to fibromyalgia (FM) and RA is the clearest illustration of the subordinated place that psychological and social factors assume in RA pain management and the dualistic conceptions of pain as being influenced by factors that are compartmentalised i.e. social, psychological, biological. Fibromyalgia is a clinical construct representing a chronic pain syndrome, characterised by chronic widespread pain, fatigue and tender points (Bergman, 2003). The cause of FM is not fully understood and was long considered an enigma, conceived as a condition without significant objective evidence of pathology. It has, therefore, been associated with a broad consideration of variables that may influence pain and its consequences.

‘A central principle in the diagnosis and treatment of musculoskeletal complaints is the recognition that ‘*arthritis*’ implies a *physical disease* process involving joint structure or physiology and that ‘*pain*’ is a complex *subjective experience* taking place in the central nervous system. In a given patient, these two processes may be *linked directly* as is the case in the *rheumatoid patient* who describes stiffness, pain, and soreness in joints that are obviously swollen and inflamed. In contrast, these processes may seem to be *uncoupled* as is the case in a patient with *fibromyalgia* (FM) who describes pains as ‘all over’ but lacks any objective evidence of joint or muscle pathology.’ (Rice and Pisetsky, 1999, p16, emphasis not in the original).

In some texts the biopsychosocial model has been promoted for use in rheumatology but in a limited way e.g. for those conditions where it is perceived there is insignificant objective evidence of disease, or ‘controversial syndromes’ i.e. fibromyalgia (Ferrari, 2000, p787). This indirectly reinforces the premise that pain in RA is approached primarily as a nociceptive phenomenon, that the pain experience is directly related to disease activity; the implication being that disease orientated intervention is the best treatment. This biomedical orientation towards pain may be evident in rheumatologists’ pain accounts.

#### **5.4.2 Pain Assessment in RA: recommendations versus actual clinical practice**

The assessment of the patient with pain is conducted for a number of reasons: 1. diagnosis and planning interventions, 2. evaluation of symptom change and 3. evaluation of the likely response to treatment (Turk and Okifuji, 2003). A core-set of measures for use in rheumatoid arthritis clinical trials have been in place since 1994 (Boers et al, 1994). These include measures of pain intensity, patient global assessment of their status, physical disability, swollen joints, tender joints, acute phase reactants and radiographs. Guidelines for the early management of RA lists essential aspects of the consultation to include a history of pain, stiffness, joint swelling and fatigue along with examination of affected joints, range of movement and extra-articular features (SIGN, 2000). These recommendations for assessment and measurements in RA are inter-related to treatment in that they have to ‘fit’ (Brown and Gordon, 2004) and, taken together, suggest a disease-orientated approach to assessment i.e. the majority of the assessments relate to the evaluation of disease processes and bodily signs of disease. In contrast, the American Pain Society (APS) guidelines for the management of pain in RA recommend a comprehensive assessment of pain where the focus is not upon measures of disease processes or physical outcomes but upon the patients’ self report of pain and consequences of pain (Simon et al, 2002: 33-41). See Appendix 7.1 for a summary of the key elements identified for the assessment of pain in RA by the APS.



Surveys of the measurement procedures used in routine rheumatology outpatient practice in Canada and Australia found the most commonly asked questions related to the duration of morning stiffness and patients' global assessment of their condition (i.e. same, worse or better). Approximately half of rheumatologists counted the number of swollen joints but less than 20% reported using any type of scale to assess pain (Bellamy et al, 1998 and 1999). This is supported by studies of clinical practice in the USA with only 8.7% measuring pain using Visual Analogue Scales, with on average less than 2% using any functional measure (Wolfe and Pincus, 1999). Overall, rheumatologists are more reliant upon counts of joint swelling and tenderness, recording morning stiffness, examining joints and observing ESR measures than self-report measures (Flowers and Wolfe, 1998; Wolfe and Pincus, 1999). The emphasis upon disease activity and biological assessment is notable, and importantly these correlate only moderately with pain measures (Coster and Bengtsson, 2001; Gaston-Johansson and Gustafsson, 1990; Smedstad et al, 1995). The suggestion that pain may often be missed or underestimated in the clinical assessment of the patient with RA would appear to be justified (Bellamy and Bradley, 1996; Wolfe and Pincus, 1999) although this seems not to have been investigated.

### **5.4.3 Pain Management in RA - only one goal amongst others**

The general approach to chronic pain management is orientated towards establishing a degree of control of painful experiences and consequences rather than cure, working with the patient as a co-manager to achieve mutual goals (Baszanger, 1989; Kugelmann, 1997). Ideally an interdisciplinary approach is adopted, combining the expertise of health professionals who consider issues wider than body dysfunction and disease (e.g. personal meanings, Clark and Cox, 2002), working to support the patient in a range of ways e.g. education, self-management training (Burckhardt, 2001). This approach is advocated for the comprehensive management of pain in RA (Simon et al, 2002). However, in texts addressing the overall management of RA, pain management is only one objective amongst others e.g. controlling inflammation and reducing the risk of joint damage (Kwoh et al, 2002; Scott et al, 1998; SIGN, 2000, Gray and Muirie, 2002). The rheumatologist must manage the significant comorbidity in RA, which makes up a significant part of his or her clinical work (McEntegart et al, 2002). Despite the treatment of pain being a priority for patients (Cox et al, 2000; Heiberg and Kvien, 2002; Minnock et al, 2003) it is acknowledged that it is unlikely to be the focus for treatment by the rheumatologists (Kvien and Heiberg, 2003), however, this has not been investigated

Examination of guidelines for the management in RA demonstrates a focus upon pharmacological treatments to slow disease processes and limit joint destruction (Kwoh et al, 2002; Scott et al, 1998). This may relate to the focus of modern medical practice upon a curative model of care i.e. where the goals of clinical medicine are primarily to cure (Rich, 2003). Although the association between reducing disease activity and improving long-term functional outcomes is well established (Fries 2000; SIGN, 2000), in clinical practice only partial control of inflammation is gained and pain is not abolished (Pincus and Sokka, 2001; Thompson et al, 2001). Within management guidelines for RA there is limited reference to use of non-pharmacological treatments in RA (Kwoh et al, 2002). This is in spite of evidence that supports the benefits of psychosocial interventions in terms of reducing patients' pain reports and increasing their ability to manage pain and improving physical and psychological functioning (Barlow et al, 2000; Keefe et al, 2001a; Lorig and Holman, 1993; Riemsma et al, 2003; Schaible and Vanegas, 2000; Simon et al, 2002).

Lessening the pain experience for the patient must always be tempered by recognition of the significance of this to the individual (Rowbotham, 2001). A small study of patients (n=29) with widespread pain, but well controlled RA-disease, found positive short-term effects from interventions specifically targeting pain e.g. education regarding pain control and coping strategies (Benjamin and Mounce, 2002). These interventions significantly reduced patients' pain intensity ratings, depression and anxiety. Nisell's (2002) report to the European League against Rheumatism on the usefulness of a specific rheumatic pain clinic noted:

'The causes of pain among patients with rheumatic diseases are varying depending upon on the disease and circumstances, demanding different treatment approaches which may be difficult to handle at an ordinary rheumatology clinic'.

Nisell (2002) continues to suggest that optimal management of pain may not be offered at the rheumatology clinic proposing that organisational and resource limitations may negatively impact upon attempts to approach pain comprehensively adopting a biopsychosocial model.



## **5.5 POTENTIAL BARRIERS TO PAIN MANAGEMENT IN RHEUMATOID ARTHRITIS**

### **5.5.1 Lack of Knowledge and Understanding about Pain**

The study of barriers to health professionals providing effective clinical pain management is associated primarily with acute pain and cancer pain research (Brockopp et al, 1998; Levin et al, 1998). Key factors identified include; the health professionals' lack of knowledge regarding the assessment and management of pain, lack of perceived knowledge and skill regarding pain assessment (Chapman et al, 2001; Gladjchen, 2001, Rutledge and Donaldson, 1998) along with failure to identify pain as a priority for treatment (Rich, 2003, p30). Pain education is considered a vital part of medical training (General Medical Council, 1997) although it is identified as lacking structure and coherence across undergraduate courses in the UK (CSAG, 1999). This reflects US studies where training and knowledge of physicians regarding pain assessment/management is considered inadequate for all types of pain (Rich, 2003). To compound this, within the undergraduate education of doctors, rheumatology education and experience is recognised to be underdeveloped and inadequate in the UK (Dequeker et al, 2000; Kay et al, 2000). Programmes to improve health professionals' knowledge about pain and thus engender more positive beliefs and attitudes regarding pain management appear to be successful (Brockopp et al, 2004, de Rond et al, 2000; Jones et al, 2000; Rutledge and Donaldson, 1998). There is limited evidence suggesting that improvements carry over into professionals' pain practice and may positively influence patient outcomes (Brockopp et al, 2004; Rutledge and Donaldson, 1998). There were no studies found addressing rheumatologists' pain knowledge, attitudes and/or beliefs.

### **5.5.2 The Complexity of the Clinical Encounter and Clinical Decision Making**

Numerous studies attest to the difficulties and frustration doctors experience at the clinic when dealing with patients with undefined chronic pain (Cooper et al, 2003; Baszanger, 1989; Sharpe et al, 1994). This has not been a subject of study in RA and is not alluded to in the literature addressing pain assessment and management. However, it is assumed that the challenges of clinical pain management are as apparent to rheumatologists as they are to other medical professionals as they share a common training background. These difficulties may be partly related to the complexities of the clinical encounter. Salmon and Hall (2003) noted that although the biopsychosocial model is useful in providing a means to understand patients' pain experiences, the clinical

encounter and decision making involves the use of both scientific and non-scientific knowledge e.g. moral considerations. In addition to considerations regarding disease management, the work of clinical practice involves negotiating patient-doctor relations, moral issues, evaluations of action or inaction, consideration of resources and contextual constraints (Baszanger, 1992; Berg, 1992; May et al, 2004; Kugelman, 1997; Sadler and Hulgus, 1992). This returns to Baszanger's (1992) advice to study 'operational knowledge' or cognitions related to the context of working with patients.

Studies of doctors' clinical decisions suggest that these are based upon multiple, competing systems of knowledge where medical judgement is influenced by situational, historical and subjective factors as well as biomedical theory (Berg, 1992; Gabbay and le May, 2004; McKinlay et al, 1996; Stein, 1986). The doctor re-interprets the patient's problem, integrating 'facts' gleaned from the patient and examination, incorporating what opportunities are known to be available for action (or disposal) relative to time constraints and organisational routines (Berg, 1992). Health professionals are also known to classify patients into 'typical, clinical types' (Bower, 1998; Bowler, 1993; May et al, 2004) which is a method used by individuals to make sense of phenomena (Berger and Luckmann, 1967). A recent and extensive study of typing or categorising patients with varied chronic illnesses is described by May et al (2004). Re-analysis of GPs' accounts of managing patients with menorrhagia, depression and medically unexplained symptoms (i.e. low back pain) found doctors classified patients depending upon; the diagnostic label, whether their symptoms were physiological and uncontested (e.g. menorrhagia), or perceived to be contested, and the possibilities for disposal or action (May et al, 2004). Similarly, others report that those presenting without clear evidence of an organic basis for symptoms may be judged unfavourably, as a person, and medical treatment considered of uncertain value (Eccleston et al, 1997; Stein, 1986).

The above-mentioned studies draw attention to the moral evaluation of patients and symptoms. Where there is difficulty establishing the organic basis of symptoms a shift of responsibility back to the patient and identification of social factors or personal fault as basis of the problem is found in doctors' accounts (Eccleston et al, 1997; May et al, 2004; Stein, 1986). The bases of such judgements are likely to rest upon multiple factors e.g. the doctor's values and sense of responsibility and their experiences in addition to medical theory. Rather than treating medical knowledge as an accepted 'fact', inquiry into its used form is promoted as a means to understanding the logic of their work, thus enabling considerations of its functions as well as the dysfunctions

(Dingwall, 1992, p167; Silverman, 1993). Overall, there is a paucity of studies which examine the frameworks that doctors use when considering patients' presentation and illnesses at clinical consultation (May et al, 2004) and none related to pain in RA. Generating rheumatologists' accounts of their actual practice and reasoning are more likely to have clinical relevance and highlight contextual issues than curtailing questioning to discrete medical knowledge of pain mechanisms in RA and/or potential treatments.

### **5.5.3 Organisational, Contextual and Resource Factors**

Factors other than knowledge, experiences, morals and values influence doctors' perceptions of patient management. Medical choice and clinical decision making is circumscribed by organisational factors, structural and contextual constraints of the system (Bates et al, 1997; Entwistle et al, 1998; Jones et al, 2004; May et al, 2004). Organisational factors e.g. resources, administrative systems etc. are known barriers to clinical pain management (Brockopp et al, 1998; Chapman et al, 2001). Although no literature was found addressing rheumatologists' clinical pain practices in relation to such factors there are well documented resource issues associated with hospital based rheumatological care in the UK. The shortfall of rheumatologists in the UK is widely recognised along with the lack of provision of multidisciplinary teams, plus limited education and advice services for patients and poor integration between primary and secondary care (Gray and Muirie, 2002; Scott et al, 1998). Rheumatology clinics lack staff, resources (e.g. personal computers) and time (Guillemin, 2000; Wolfe and Pincus, 1999). Rheumatologists' consultations last on average only 15 minutes (Stowers et al, 1999). During this time multiple tasks are conducted e.g. blood tests, x-rays, medication alteration, injections and referrals to other health professionals (Hehir et al, 2001). Patients themselves report feeling rushed and are conscious that clinics are busy environments (Donovan, 1991). These factors may shape how rheumatologists perceive pain management in RA and have not been explored.

## **5.6 SUMMARY AND CONCLUSIONS**

There are few studies exploring doctors' conception of chronic pain and most of these have focused upon non-diagnosed conditions and none have specifically addressed non-cancer, chronically painful diseases like RA. No literature was found relating specifically to rheumatologists' pain perceptions and research suggests that generalisations should not be made from studies of doctors working in other specialities. The two dominant

models of pain i.e. the biomedical and biopsychosocial models may influence the way that health professionals' think about chronic pain. However, the nature of the inquiries examining doctors' pain perspectives over the past 10 years have failed to provide an integrated picture of how doctors conceive of the multiple dimensions of pain, constrained by the methods used and the specificity of the questions addressed. Review of the pain-discourse in rheumatological texts suggests that despite current pain theory, that locates pain as both a physiological and experiential phenomenon, pain in RA is viewed in a biomedical way i.e. there is a disease-oriented frame of reference. This approach is not appropriate for long-term pain management where psychological and social factors can become more important to the patient, and relate more closely to quality of life, physical and psychological wellbeing than do the disease variables. Whether this approach is evident in rheumatologists' accounts of pain is not known. The complexity of dealing with the patient with chronic pain is not complete without appreciation of the nature of the clinical encounter and clinical decision making. Both scientific and non-scientific knowledge as well as considerations of situational and organisational factors shape doctors' actions and decisions. 'Operational knowledge' refers to contextual-cognitions that shape clinical practices and is arguably more relevant to clinical care than conceptions of 'ideal' or theoretical approaches to pain. Little is known about rheumatologists' conception of pain, whether scientific, non-scientific and/or operational. Exploration of the used-form of pain perceptions could be facilitated through questioning rheumatologists about experiences and examples related to clinical practice, ideals and realities, frustrations etc. Where the aim is to generate a diversity of doctors' pain accounts the sampling strategy must aim for a sample with varied gender, age, length of experience, types of patients normally seen and work location (e.g. rural, city and teaching hospitals).

## **6 CHAPTER SIX - PATIENT-CENTRED CARE AND PAIN MEANINGS**

### **6.1 INTRODUCTION**

Patients with rheumatoid arthritis are in frequent contact with hospital-based rheumatologists from the point of diagnosis onwards; 52% of patients consult with rheumatologists 1-3 times a year and 31% are seen 4-6 times per year (NRAS, 2003). The usefulness of knowledge regarding patients' and rheumatologists' meanings of pain is discussed here, as is consideration of how this type of knowledge supports a patient-centred approach towards caring for the individual with chronic pain. A patient-centred approach advocates patients and doctors working together, sharing responsibility for healthcare and communicating effectively. Although knowledge about patients' and rheumatologists' pain meanings does not lead to prediction of their respective behaviours, it is argued that such knowledge can contribute to effective communication by identifying the educational needs of both parties and will promote understanding of patients' experiences of pain. The importance of effective communication about pain at the clinic is highlighted by studies that suggest patients' pain is under-assessed and under-estimated by healthcare professionals. Although government and professional bodies promote patient-centred care, organisational barriers may affect its implementation and so shape patients' and doctors' extant pain meanings related to clinical care.

### **6.2 PATIENT-CENTRED CARE IN CHRONIC ILLNESS**

Increasing numbers of those with chronic illness in western societies have required medical intervention to move away from biomedically orientated 'cure' models towards a 'care' approach where the patient actively co-operates with healthcare; assuming the role of 'co-healer' (Helman, 2000, p 67). Although there is no agreed model for the management of chronic diseases within the NHS (Lewis and Dixon, 2004) the focus of care is upon the subjective patients' view of health/illness and quality of life (Sullivan, 2003). This focus is supported in the concept of 'patient-centredness', an approach which emphasises the patient's role in self-monitoring and self-managing their condition as well as collaborating with health professionals (Grol, 2001). The approach promotes shared power and control within healthcare with effective communication in encounters being a fundamental component (Gillespie, 2002).

Mead and Bower (2000) identify five dimensions of patient-centred care (see Table 6.2).

**Table 6.2 Five Dimensions of Patient-Centred Care (Mead and Bower, 2000, p1088-1091)**

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Key Conceptual Dimensions of a Patient-Centred Approach to Care

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- Adopting a biopsychosocial perspective towards health/illness.
  - Considering the personal meanings of illness for patients.
  - Sharing power and responsibility with patients.
  - Attending to socio-emotional components of consultations to optimise therapeutic relations.
  - Awareness of how the doctors' qualities may influence clinical practice.
- 

In these ways, the patient-centred approach emphasises the importance of the clinician knowing and understanding something of patients' illness experiences and what patients understand of their illness/disease together with their concerns, expectations etc. This understanding enables effective communication and discussion of what the key issues might be for the patient and aid the planning of appropriate support. In addition to this, the expert must be aware of the interpretive frameworks which shape their views about an illness/disease and consider how such ways of thinking may impact upon how they deliver care (Hanson and Gerber, 1990).

### **6.2.1 Evidence Supporting the Patient-Centred Care Approach**

Patient satisfaction and adherence to advice is enhanced by patient-centred approaches to care which are often underpinned by effective communication (Lewin et al, 2004). Effective patient-doctor communication requires the doctor to understand patients' views, expectations and perceptions of their problems and treatments (Donovan et al, 1989). When patients with RA believed that they were not understood by the doctor or that they and the doctor held different views, this was then associated with doctors failure to reassure; patients also rejected things which were said with which they did not agree (Donovan, 1991). Patients are more satisfied when medical explanations do not conflict with their own understanding (Salmon et al, 1999) and, when doctors and patients have different views about disease or treatment this can result in problematic interactions (Helman, 2000: 103-107; Tuckett et al, 1985b). How the individual evaluates what is said by the doctor at consultation is dependent upon how they interpret and evaluate the doctors' opinion and this, in turn, is influenced by their interpretive framework and the degree to which this contrasts with the doctors (Tuckett et al, 1985a).

### **6.3 COMPARING PATIENT-DOCTOR PERSPECTIVES ABOUT PAIN**

There are few studies examining patients' and doctors' perspectives on pain and most are restricted to comparing pain intensity ratings. These comparative studies commonly relate to cancer pain or acute post-surgical pain (Rutledge and Donaldson, 1998) and fail to compare the multiple dimensions of the pain phenomenon. Overall, it is widely accepted that both acute and chronic pain is under-assessed and under-estimated by health professionals (Brunelli et al, 1998; Drayer et al, 1999; Nekolaichuk et al, 1999; Rutledge and Donaldson, 1998). Mäntyselkä et al (2001) studied pain intensity ratings of patients and the general practitioner the patient was consulting and reported that for 20% of patient visits, general practitioners under-rated the patients pain intensity in chronic pain conditions by at least two points on a 10 cm Visual Analogue Scale. In addition, the higher patients' pain ratings were, the greater the discordance found.

Eccleston et al (1997) studied how patients with chronic pain and pain experts understood the causes of chronic pain and described, in detail, patients' and experts' accounts. The findings emphasised the disparity between accounts. Patients proclaimed their pain had a real and physical cause and strongly rejected suggestions of the psyche influencing pain experiences. Pain was viewed as a symptom of an underlying dysfunction that had yet to be identified and patients felt angry that what they viewed as a 'powerful and technological medicine' could not 'repair' them. In contrast, the pain professionals (e.g. anaesthetists and pain therapists) suggested that pain was a 'dysfunctional reaction' to a pain-provoking event associated with learned maladaptive habits (Eccleston et al, 1997). In this way, pain ceased to be viewed as a symptom of body dysfunction and the best approach to treatment was identified as non-biomedical and responsibility for care was shifted back towards the patient. This example highlights the many different dimensions of pain meaning that can diverge between lay and expert perspectives. Differences emerged regarding the mechanisms of pain, what it signified and what it could be used for, how it was moderated and how it could be treated within associated patient-doctor relationship issues. This type of work is needed in RA since the study by Eccleston et al (1997) focused upon pain of a non-pathological origin and the professionals sampled were primarily pain specialists.

#### **6.3.1 Divergent Patient-Rheumatologist Views About RA and Pain in RA**

Differences between patients' and doctors' perspectives regarding chronic illnesses are found for various conditions e.g. fibromyalgia (Dobkin et al, 2003) lupus (Yen et al, 2003) and multiple sclerosis (Rothwell et al,



1997). Similarly, in RA, patients and rheumatologists have been shown to hold differing views regarding multiple illness-related topics. Patients and doctors make different assessments of patients' physical and mental health status, even when both parties use the same simple assessment scales (Kwoh et al, 1992) they rate the importance of health variables differently (Hewlett et al, 2001). Patients and rheumatologists have different beliefs about the risks of treatments for RA (Fries et al, 1990; Pullar et al, 1990) and identify different educational needs (Potts et al, 1984; Silvers et al, 1985).

Few studies were found comparing any pain dimensions in RA. Lambert et al's (2000) study of a mixed group of medical specialists (n=14) and 'arthritis' patients' (n=12) and their respective views on arthritis care, found both agreed that pain reduction was an important treatment outcome. Although this American study is limited by the numbers of patients recruited, and fails to define what type of arthritis the patients had, it highlighted the disagreement between the groups regarding several issues i.e. whether pain was an inevitable part of ageing and the usefulness of drug therapy. Another US study examined the congruence between rheumatologists' and rheumatology patients' ratings of health status, pain intensity rating and worry (half of the sample had RA; Suarez-Almazor et al, 2001). After a consultation each party completed self-report measures. Statistically significant differences were observed with rheumatologists rating patients' health status as higher and pain lower in comparison to patients' scoring. The authors suggested a need to enhance patient-doctor communication during consultations and urged doctors to take greater account of patients' perceptions of illness. Kwoh and Ibrahim (2001) examined whether rheumatologists could align with rheumatology patients' selection of important health and symptom outcomes after a consultation. Doctors often failed to parallel the patients' selected key outcome goals. These studies only hint that pain perceptions may differ between rheumatologists and patients with RA and fail to explore in any depth what is understood about pain and why.

### **6.3.2 Implications of Divergent Patient-Doctor Pain Perspectives**

Numerous studies document patients' distress, frustration and humiliation when they perceive that the doctor does not believe their pain reports or that their pain is legitimate or 'real' (Howell, 1994; May et al, 2000; Rhodes et al, 1999; Söderberg et al, 1999; Walker et al, 1999). Divergent conceptions about the nature of the pain problem are associated with patients feeling hostile and distanced from the medical world (Rhodes et al, 1999; Walker et al, 1999). As a consequence, doctors report feeling frustrated and question the motivation of the patient



seeking help together with the legitimacy of their complaint (May et al, 2004). Notably, all of these findings relate to patients with un-defined chronic pain conditions (e.g. chronic low back pain). As such, these findings are unlikely to be representative of pain perceptions related to a progressive, painful disease like RA.

Clinical interviews for pain are advocated covering both factual topics (e.g. what medications are used) as well as attending to patients' perceptions of the cause of pain, its consequences and personal pain meanings; the aim being to engage with the patient's perspective (Turk and Okifuji, 2003). Unless the doctor is aware of the patient's subjective experience of pain, pain will remain untreated (Glajchen et al, 1995). However, patients difficulties in conveying pain experiences are well documented and relate to the inadequacy of language to describe their problems and the difficulty of talking about personal and emotional experiences (Craig, 1999; Morse and Mitcham, 1998; Scarry, 1985). Whether patients with RA find it difficult to talk about pain or whether rheumatologists have difficulties in assessing pain are not known and require investigation.

### **6.3.3 Why Perceptions of Illness Differ Between Patients and Professionals**

Patients' and health professionals' views on illness and pain may differ for a number of reasons. It is suggested that doctors interpretation of illness is based primarily upon causal ideas and scientific logic developed through medical and professional training (Kleinman, 1980). In this way, the doctor assigns meaning and forms interpretations based upon understanding the disease and its symptoms, meanings which may be dissimilar to the patients' (Toombs, 1993). The medical and scientific worldview has strongly shaped definitions of pain which have diffused into lay language (Peters et al, 1998). Patients are known to incorporate medical elements into their own models for explanation of symptoms (Salmon and May, 1995). However, patients' pain conceptions appear more complex, interwoven with biographical and experiential features, such conceptions do not always concur with the medical scientific view (Honkasalo, 2000; Jackson, 1994). The patient both experiences and assigns meanings and develops a changing, dynamic collective of personal meanings of illness (Cassell, 1979). A diverse range of uniquely personal factors can influence pain meanings - priorities, expectations, past history, context etc. For these reasons some meanings may be shared and others will be formulated from a unique biographical base. To make sense of these pain meanings an exploration has to be made of accounts given by the individual along with study of how group's accounts (i.e. patients and professionals) may vary.

## **6.4 PROMOTION OF AND BARRIERS TO PATIENT-CENTRED CARE**

### **6.4.1 The Promotion of Patient-Centred Care in Rheumatology**

An overall trend towards making healthcare more patient-centred is evident at the level of government NHS policy. The NHS Plan placed a legal duty on NHS organisations to consult with and involve patients in improving patients' experience of healthcare (Commission for Health Improvement, 2002; Department of Health, 2000). The concept of the 'expert' patient emerged, where patients with knowledge of their condition and understanding of its management would work in partnership with health providers (Department of Health, 2001). This acknowledged that patients could provide valuable insights into their needs and evaluate their care (Brady 1998; Richards, 1999). Rheumatology professional bodies have also pursued knowledge of patients' perspectives to inform clinical and research practice (Carr et al, 2003; Kirwan et al, 2003) and to promote patient-centred approaches in preference to disease-focused models of care (Callahan and Pincus, 1997; Foster et al, 2003; Gray and Muirie, 2002).

### **6.4.2 Barriers to Delivering Patient-Centred Care**

The actions and clinical practice of health professionals are not determined solely by knowledge, medical training or policy but by organisational and institutional factors (Baszanger, 1992; Berg, 1992; Jones et al, 2004; May et al, 2004; Sadler and Hulgus, 1992). The resources and interventions available, staff, time and economic constraints can all influence clinical work and therefore may shape clinical-contextual meanings of pain (Baszanger, 1992 and 1989; Jones et al, 2004; Vrancken, 1989). It is well recognised that resources are limited in rheumatology (in Scotland there is one consultant whole time equivalent for 213, 300 patients in contrast to the recommended ratio of 1: 80, 000; Gray and Muirie, 2002). A summary of the deficits in current service provision for people with RA in Scotland is presented in Table 6.4.2, compiled from the Needs Assessment Report for RA (Gray and Muirie, 2002).

**Table 6.4.2 Summary of the Deficits in Current Service Provision for People with RA in Scotland (Gray and Muirie, 2002, p12)**

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Problems with Existing Services in Scotland

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- Insufficient knowledge and skills base amongst many professionals.
- Poor coordination and integration between primary and secondary care.
- Current services not as 'patient-centred' as patients would like.
- Services not consistently integrated with patient self-management.
- Standards of care vary throughout Scotland.

Poor understanding of what can be done to improve the patient's journey and outcomes in RA by health professionals, planners and policy makers compounds problems.

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## **6.5 PATIENTS' NEEDS AND DOCTORS' RESPONSIBILITIES**

Patients with chronic illnesses want doctors to understand diseases and treat problems whilst also providing advice and support, empathy and time; accompanying them through illness (Arthur and Clifford, 2004; Charon, 2001; Ironside et al, 2003). Health professionals' understanding of patients' experiences enables them to consider the patient as a person, with an individual lifestyle and illness experience and not as a disease-affected body (Quest et al, 2003). Patients also have an obligation to know what they should expect to receive and to learn what they can do to help themselves (Holman and Lorig, 1997). However, it is arguable that it is always the doctor's responsibility to minimise the difference between patient and expert perspectives on disease/illness and to try and understand the patient's experience (Dekkers, 1998; Toombs, 1992). The doctor ultimately exercises the power in deciding what is assessed and measured, the doctors' values and preferences are dominant in deciding what to pursue and to value in the consultation, with the consequent evaluation guiding therapeutic discussions (Brown and Gordon, 2004; Kirwan et al, 1990). Without adequate exploration of the patients' perspectives and due verification of the doctors' perceptions of a problem, non-treatment, unnecessary interventions or mistreatment is probable (Berkanovic, et al, 1995).

The doctor is identified by the patient as a key provider of information and education, influencing patient actions and understanding; the consultation is a place of implicit learning, where patients internalise the messages relayed by the doctor (Brown, 1995; Buckley et al, 1990; Skelton, 1998; Waitzkin et al, 1994). The new emphasis upon consumer involvement in health and the concurrent destabilisation of professional authority suggests that

professionals dominance in healthcare is waning (Davies, 2003). However, health professionals continue to lead in the clinical management of patients' pain and are the primary source of information and education in facilitating self-management (Burckhardt, 2001; Simon et al, 2002).

## **6.6 SUMMARY AND CONCLUSIONS**

A patient-centred approach to care is widely promoted for individuals with RA and focuses on the subjective patients' views of illness and on encouraging the patient to have an active role in self-management and care. This approach is partly reliant upon effective patient-doctor communication and requires the clinician to be cognisant of patients' personal meanings of illness in addition to understanding how his/her own interpretive framework can influence clinical practice. Studies of patients with undefined chronic pain suggest that patients' and doctors' pain perspectives can be widely discordant and hence associated with various negative effects. There were no in-depth studies found regarding pain perceptions in RA although there is evidence that patient-rheumatologist views are discordant in relation to a range of disease-related topics. It is suggested that chronic pain in general and pain in RA is under-estimated, poorly assessed or even 'missed' by health professionals. Pain is a topic that patients can find difficult to communicate and discordant patient-doctor views may further compound this. Knowledge of patients' and rheumatologists' pain meanings could provide insight into their educational needs and help the clinician to understand the patients' perspective, promoting provision of appropriate support and information. An insight into experts' conceptions of pain may promote reflection by doctors of how their own pain conceptions may influence clinical pain work and shape patients' understanding as well as the exploration of gaps in understanding and/or organisational barriers to care. Knowledge of what shapes individuals' pain meanings may be useful where the intention is to attempt to negotiate new or more adaptive/'correct' pain conceptions.

Exploration of personal 'pain meanings' demands a research philosophy and corresponding methodology that is compatible with inquiry into aspects of human subjectivity. An overview of constructionism, qualitative inquiry and related methodological issues are presented in the following chapter as a precursor to presenting the study methods.

## **7 CHAPTER SEVEN - RESEARCH THEORY AND METHODOLOGICAL JUSTIFICATION**

### **7.1 INTRODUCTION**

Qualitative research still lacks widely accepted quality standards thus leaving this approach open to criticism. Its failure to address issues wider than the technical features of a study can leave the reader unable to fully evaluate the appropriateness and usefulness of findings (Popay et al, 1998). This chapter describes and defines the theoretical basis of the current study of pain meanings (i.e. constructionism) and justifies the methodological approach adopted and the methods selected. The argument for pursuing a pragmatic, interpretive qualitative approach as opposed to following a specific traditional paradigm e.g. phenomenology is made, whilst explaining how several traditional interpretive paradigms influenced the methodological approach. The orientation of this study regarding issues of validity, reliability and generalisability is discussed. Details of the actual study processes and methods are not included here but are presented in Chapter Eight.

### **7.2 EXPLORING MEANINGS AND CONSTRUCTIONISM**

Constructionism (also referred to as constructivism) is an ontology compatible with the nature of meanings and what can be known about them (Bryman, 2001, p502). Constructionism views all knowledge as being dependent upon human practices. It is therefore constructed by humans through their interactions and their experiences in the world (Crotty, 1998). Knowledge relating to human action and the social and cultural aspects of society is assumed to be dependent upon individuals and their relationships, experiences, context and time and, as such, represents a 'relative truth' (Crotty, 1998). For this study a 'subtle realism' is adopted where it is accepted that the individual perceives their world from their own particular view point, however, this perception is constrained by available personal and socio-cultural resources (Hammersley, 1992 cited in Seale, 1999, p26). The sense of 'truth' adopted in this study is founded in gaining an understanding of the personal and shared meanings of pain from rheumatologists' and patients' spoken accounts. It is assumed that diverse types of knowledge and experiences influence an individual's frame of reference against which background they talk about their experience and understanding of pain, and thus, these dynamic meanings are both socially and historically constructed. In keeping with a constructionist view of knowledge, meaning is not discovered nor determined but

is constructed and conveyed within a primarily social context (Crotty, 1998). Meanings of pain generated through this study are therefore 'constructed' by the researcher and participants, albeit using methods to contain and account for the influence of researcher; enabling the reader to assess the inherent subjectivity and value of the findings.

### **7.3 AN INTERPRETIVE RESEARCH PARADIGM FOR THE STUDY OF MEANINGS**

A paradigm represents the researcher's 'worldview' and therefore has bearing on what a researcher believes he/she can explore and investigate as well as what is outside the scope of an inquiry (Guba and Lincoln, 1998). Each paradigm 'exists' with characteristic processes and forms of representation and interpretation. The interpretive research paradigm acknowledges the unique nature of humans to give subjective meaning to phenomena/events and hence gives value to understanding human action and the interpretation of events/phenomena (Bryman, 2001, p13). Interpretivists attempt to understand the lived experience and individuals' understanding from the perspective of those who are living it i.e. respondents' meanings are the primary focus of study (Schwandt, 1998). The interpretive paradigm encompasses many research approaches with corresponding methodologies (e.g. hermeneutics and phenomenology, Higgs, 2001, p49). Argument exists both for and against adopting a specific interpretive world-view (e.g. phenomenology) and related methodology and there is no consensus regarding the most 'correct' approach to any particular subject.

Paradigm based research may provide a sense of order which is evident throughout the research processes (Grbich, 1999). Others argue against this and suggest adopting a 'paradigm of choices', where methodological appropriateness is the primary concern i.e. where the quality of the research is based upon judgement of the suitability of methods for the purposes of the inquiry (Mason, 1996; Patton, 1990), or where selection of any one particular theoretical paradigm may limit interpretive opportunities (Avis, 2003). The alternative is to adopt an approach that can accommodate the dynamic nature of subject/researcher relations as well as the necessity for flexibility of design, which may best enable advancement of knowledge (Grbich, 1999). For this study a flexible approach is adopted which can be broadly described as a pragmatic, interpretive, qualitative approach where the purpose of the study and the nature of the research questions guide methodological decisions.

### 7.3.1 An Interpretive Qualitative Research Approach

There is no single definition of qualitative research and it is used by multiple disciplines in a variety of ways, with different emphasis and approaches to methodology and methods (Grbich, 1999). Despite the absence of a standard approach to qualitative research it is identified by a number of characteristics, outlined in Table 7.3.1. These characteristics are reflected in the methodology of this study, at the same time drawing inspiration and influence from several traditional paradigms.

**Table 7.3.1 Characteristics of an Interpretive, Qualitative Research Approach (compiled from - Bryman, 2001, p20 and 264; Denzin and Lincoln, 1998; Higgs, 2001; Mason, 1996, p4; Silverman, 1993)**

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Characteristics of Interpretive Qualitative Research
<hr/>
Philosophical Basis
<ul style="list-style-type: none"><li>• Operates from an ontological position of constructionism where the phenomena is not separate from those involved in its perception i.e. meaning is formed through the interaction between people, their own thinking and their life-world.</li></ul>
Broad Paradigmatic Orientation
<ul style="list-style-type: none"><li>• An interpretive position is concerned with how the individual interprets, understands, experiences or produces meanings in their social world.</li></ul>
Nature of the Research Approach
<ul style="list-style-type: none"><li>• A naturalistic approach is committed to naturally occurring 'data' e.g. accounts gathered about people's life experiences in a non-experimental situation.</li><li>• Sensitivity to social context and the relationship between the researcher and the subjects is inherent within the study.</li></ul>
Nature of Findings Generation
<ul style="list-style-type: none"><li>• The methods used are flexible, enabling an effective route to theory or explanation e.g. interviews.</li></ul>
Nature of Analysis
<ul style="list-style-type: none"><li>• Analysis and generation of findings using an inductive, interpretive approach.</li><li>• Analysis is commonly circular i.e. repeated return to the accounts throughout analysis, an iterative process.</li></ul>
Nature of Findings
<ul style="list-style-type: none"><li>• Qualitative explanations often deal with complex, detailed contextual findings.</li><li>• Varied levels of abstraction from respondents' words to theory development.</li></ul>
Approaches to Quality Issues
<ul style="list-style-type: none"><li>• Lack of consensus regarding acceptability of criteria for quality control, varied standards and rationale described although there is agreement that 'trustworthiness' or the value of the study findings must be demonstrated.</li></ul>

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### **7.3.2 Inspiration and Influence from Traditional Paradigms**

Choosing not to commit the study to any one particular theoretical paradigm may promote flexibility of design, however, this risks ignoring the wide and often competing theories on how social entities can be understood. As the researcher's 'worldview' fundamentally influences the entire research process this worldview should be exposed (Mason, 1996). Several interpretive traditions and related methodologies influence this study's design: symbolic interactionism, and related grounded theory methodology, phenomenological and hermeneutic-phenomenological traditions.

#### **7.3.2.1 *Symbolic interactionism and grounded theory***

Symbolic interactionism is an interpretive branch involving the understanding of meaning and its making. The inquirer's role is to gain an appreciation of the subject's viewpoint, how they see the world and how they interpret it.

Grounded theory (developed by Glaser and Strauss, 1967) is one of the most commonly cited methodologies used in qualitative healthcare studies and is developed from symbolic interactionist thinking. It is a specific form of ethnographic inquiry having a number of explicit steps used to develop theory. The emphasis in a grounded theory approach is based on participants' accounts as the source for theory development. Since its development grounded theory has undergone several modifications and is documented in different formats and controversy remains regarding different versions (Bryman, 2001, p397). The suggestion that all relevant theories and concepts should be 'ignored' or the researcher should suspend awareness of these until later stages of analysis is difficult to achieve (Grbich 1999). Grounded theory is not always used in a pure form, with researchers imposing variations and has been criticised for being used as a means to confer respectability rather than to convey useful information about methods of analysis in the qualitative research field (Avis, 2003; Bryman and Burgess, 1994). Despite these criticism, elements from grounded theory methodology are particularly suited for relatively small scale projects exploring meanings and provide a rigorous approach for the generation of concepts where inductive methods, involving synchronous generation and analysis of findings are used (Bryman, 2001, p396; Grbich, 1999). Grounded theory provides a detailed guide for the entire qualitative data analysis process (Strauss and Corbin; 1990). Several of the principle techniques and methods of grounded theory are particularly valuable in assisting the movement from grounding in respondents' words to higher levels of abstraction and making clear



how these links have been made (Seale, 1999, p88-105). Grounded theory methods integrated within this study include the constant comparative method, theoretical sampling and theoretical saturation (Straus and Corbin, 1990).

### **7.3.2.2 Phenomenology and hermeneutic phenomenology**

Phenomenology and hermeneutic-phenomenological traditions have been influential in studies of patients' pain accounts (e.g. Hellström, 2001; Honkasalo, 2000; Kugelmann, 1999). Within phenomenology the emphasis is on returning to the 'thing' or phenomenon as they present themselves to the subject. This form of study focuses on the subject and how they consciously experience reality, inviting the subject to engage with the world and make sense of it directly and immediately (Crotty, 1998). This approach is assumed in this study relative to the participant interviews by asking respondents to talk about their experiences and understanding, as they see them. Hermeneutics is associated with an interpretive act that is applied to the non-obvious or not immediately visible meaning. It emphasises awareness that, for each 'meaning', there is an interpretive act shaped by history and knowledge of what it is to be human (Dekkers, 1998). This emphasis on meanings is an important sensitivity within this study as the researcher fully appreciates that accounts can be attended to on two different levels:

1. What is immediately known i.e. the essence of things as they are experienced or what the respondent understands of events, phenomenon etc; and
2. The hermeneutic reading, attending to interpretive processes inherent within each meaning i.e. considering what social-cultural, historical, contextual influences are brought to bear upon the meanings presented.

## **7.4 THE QUALITATIVE INTERVIEW**

An interview is a special form of conversation used to generate data about the social and experiential world through talk (Holstein and Gubrium, 1998, p113). Individual, face-to-face interviews can offer insight into individual's thoughts, how they interpret an event or phenomenon, their experiences and, potentially, offers suggestions as to the basis of their actions (aspects that cannot be observed; Murphy et al, 1998). Qualitative approaches to interviews in health-related research characteristically employ semi-structured or unstructured interviews (Britten, 1995, p251; Holloway and Fulbrook, 2001).

Structured interviews are deemed unsuitable for the purpose of gaining in-depth understanding of how an individual experiences or thinks about complex phenomena e.g. pain. They tend to ignore the individuality of interpretation and meaning.

Murphy et al, (1998, p 113-115) provides a summarisation of several critical points regarding the structured interview format as follows:

- potentially it produces misleading accounts as the individual may interpret questions differently or ascribe different meaning to questions asked;
- it lacks the flexibility to allow the interviewee to direct the emergent ideas;
- it does not generate depth of understanding around any particular point;
- the researcher may have pre-defined topics of importance, not the respondent; and
- loss of context of a response might affect or say something about the intended or unintended meaning/s.

In contrast, the semi-structured interview commonly presents open-ended questions to the interviewee through use of a loose structure. This gives the interviewer the flexibility to probe or further pursue issues in more detail or to follow-up ideas and move into unanticipated areas; ideally this would be done in a non-directive way allowing the respondent to use their own words (Britten, 1995, p251; Bryman, 2001, p312-322). In this way, the respondent has the potential to express their own views and/or to direct responses (Britten, 1995). An interview guide may be used to ensure coverage of topics relevant to the study or to key areas of interest. There is no set formulated ordering or wording for question delivery, as in a structured interview (Mason, 1996; Seale, 1998).

#### **7.4.1 Threats to the Trustworthiness of the Qualitative Interview Method**

Threats to the 'truthfulness' and relevance of accounts generated through qualitative interview are a product of the features that facilitate the production of valid and grounded insights e.g. the researcher actively constructing the findings with the interviewee (Miczo, 2003). This raises the question of whether the ways the questions/topics are presented actually addresses what is intended. Potentially, the researcher may bias or alter what is produced, or not talked about and misinterpret what is said (Murphy et al, 1998). The qualitative interviewer is therefore required to consider the impact of their presence, their biases, the presentation and nature of questioning and how

they influence what is generated i.e. adopt a critical approach to the appropriateness of the method, procedure and delivery (Britten, 1995; Mason, 1996).

#### **7.4.2 The Status of Interview Accounts: 'truth' or something else?**

There are two primary perspectives regarding the status of findings generated via qualitative interviews:

1. to consider the findings as a product of social interaction where respondents actively present themselves in a competent light to the listener, i.e. the interview itself is treated as a topic of study rather than a resource (Seale, 1998; Silverman, 1993); and
2. the more liberal view that respondents' accounts will have some elements of what is 'real' i.e. interview accounts can tell something about the phenomena in question but must be considered in light of context (what are they saying, to whom etc, Hammersley and Atkinson, 1995).

The second view (noted above) is adopted in this study bearing in mind the general acceptance that interview findings cannot and should not be directly used to judge what 'actually happened' or was experienced (Holstein and Gubrium, 1998). For example, the patient's account of their consultation experience is not considered to be a reflection of what would have been observed. It can however reveal something about a particular event or phenomena. Interview accounts are not viewed as explicit truths, they do not reveal participants' perceptions, to which there is no direct access, but they can be reflective of these (Silverman, 1993). In this way, what is said must be interpreted by considering why the respondent might have said it, and by considering who or what the interviewer is within the cultural, social and moral values of society which may perhaps influence what is said (Carr et al, 2002; Seale, 1998). The accounts are co-creations, a product of the interview context, influenced by the researcher's presence and questioning and the interpretive filters of the researcher and respondent and the resources available to both within society (Garro and Mattingly, 2000). As such, the reflexive researcher must be wary of treating interview material as unproblematic and needs to consider the circumstances of account co-creation, as well as power issues, trust, the need to protect identity and to portray a certain 'acceptable' face, or to defend moral reputation (Miczo, 2003; Murphy et al, 1998, p123; Radley and Billig, 1996).

## 7.5 USING QUALITATIVE ANALYSIS TO GENERATE FINDINGS

Qualitative research commonly generates large amounts of textual data that often fails to conform to any strict pattern or form (Murphy et al, 1998, p131). Therefore, processing interview transcripts into coherent and useful findings can be a challenging task for the researcher who is the primary analytic tool (Bryman, 2001). Consistent with constructionism, and belief in multiple realities, there is no 'true' interpretation and hence no consensus upon how qualitative analysis is done. The approach to analysis is dependent upon what the researcher believes can be known about through accounts, theoretical sensitivities and, to what degree, findings are processed e.g. description or theory development (Lofland and Lofland, 1985).

Characteristically, interpretive qualitative analysis involves:

- Concurrent, interactive account generation and analysis (Miles and Huberman, 1994);
- Inductive i.e. data/account driven analysis (Crabtree and Miller, 1992);
- Progression from un-interrupted accounts towards the development of themes/categories which are have been ordered with higher levels of abstraction (Boyatzis, 1998).

### 7.5.1 Key Processes in Interpretive Qualitative Analysis

In studies of patients' experiences of chronic pain variously defined analytical methodologies are found e.g. grounded theory (Howell, 1994), interpretive phenomenological analysis (Osborn and Smith, 1998) and phenomenological-hermeneutic method (Söderberg et al, 1999). However, irrespective of the proposed method when each is deconstructed and contrasted, common features emerge regarding the stages of the analytical procedure. Table 7.5.1 illustrates comparison of the language used to describe the successive stages of qualitative analysis of three methods.

**Table 7.5.1 Comparison of the Descriptors of the Primary Components of Three, Account Driven, Qualitative, Interpretive Analytical Procedures (developed from Boyatzis, 1998; Söderberg et al, 1999; Strauss and Corbin, 1990)**

Stage of the Process	Qualitative, interpretive thematic analysis	Phenomenological-hermeneutic analysis	Grounded theory - the constant comparative method
Stage 1	Read the text as a whole to gain a sense of understanding.	Gain naïve understanding - read the text to establish a sense of the whole and parts.	Immersion in the text, reading accounts attending to the substance of what is said.
Stage 2	Identify emerging themes, compare across samples, condense/cluster themes and become more abstract.	Specific identification of parts of account and/or patterns and evolve explanations for the account's nature (interpretation).	Breaking down the accounts by labelling to enable comparison with similarly tagged parts. Move towards more conceptual groupings and make connections between these.
Stage 3	Show how the themes interact or are inter-related.	Integrate the initial understanding with the structural analysis findings to generate a comprehensive understanding of the whole.	Reconstruct the whole by identifying a core concept that relates to others.

Similar steps in the analytical process were found across a range of interpretive analytical methods differing only in the language used and the degree of detail given to guide the procedure. Six key stages were identified (listed in Figure 7.5.1) and are used to inform this study's analysis.

**Figure 7.5.1 Six Key Stages Involved in Interpretive Qualitative Analysis**

- Read the whole transcript/account for a sense of the whole, read and re-read to attain the essences of meaning and help identify units of 'meaning'.
- Extract specific statements or units of meaning or phrases relating to the topics of interest (i.e. related to the study questions and aims) and examine these together, comparing and contrasting.
- From these meaning units or de-contextualised parts of text, abstract what they say or what they may mean to gain understanding through interpretation.
- Formulate these meanings or phenomena into themes that are more defined i.e. summaries of the key findings in the text, cluster themes into higher order categories i.e. the essence of these.
- Integrate the themes and/or categories and work out the interactions or relationships that exist between them.
- Present the synthesis of categories with existing work/research to aid new understanding of phenomenon or a new way the topic can be viewed.

### **7.5.2 Levels of Processing of Accounts - description, explanation and theory**

Qualitative researchers may aim to process accounts to different degrees dependent upon their research aims and range from description of patients' experiences using their own words (Henriksson, 1995) to theory generation and testing (Howell, 1994). The degree to which findings are processed has implication for the degree of usefulness and contribution to existing knowledge or theory. Accurate descriptions, organisation of individuals' experiences or views may be useful for new areas of inquiry, whereas, thematic description or interpretive explanation or theory may reveal new ways of viewing a phenomenon or provide explanation for experiences or action (refer to Table 4.6.5, Sandelowski and Barroso, 2003). Given that there is an existing base of literature regarding patients' pain experiences and explanations (reviewed in Chapter Four) the aim is to build upon existing work to at least the level of thematic description with inter-related explanations where possible. The study of rheumatologists' pain conceptions is novel and therefore requires a degree of detailed description. In addition, the parallel study of patients' views allows for theme comparison across the two sample groups and moves towards interpretive explanations to account for pain perceptions which may be inter-related e.g. in relation to clinical pain-related encounters.

### 7.5.3 Using Software to Assist in Qualitative Analysis

Several software packages are available which support textual analysis through the labelling/tagging or coding of sections of text, enabling storage, retrieval and organisation. Some also advocate a role in assisting theory building e.g. Atlas.ti®, NVivo, Ethnograph (Bryman, 2001). See Table 7.5.3 for a summary of the potential advantages and disadvantage of using Computer Aided Qualitative Data Analysis Systems (CAQDAS).

**Table 7.5.3 Summary of the Potential Benefits and Disadvantages of Using of Computer Aided Qualitative Data Analysis Systems (CAQDAS, primary references, Bryman, 2001; Murphy et al, 1998, p144-148).**

Benefits of Using CAQDAS	Disadvantages of Using CAQDAS
<ul style="list-style-type: none"><li>• More efficient handling of code and retrieve processes regarding textual material dispensing with manual labour of cut and paste.</li><li>• Ease of coding, retrieval and organisation of chunks of text may promote thinking about the meaning of a section of findings.</li><li>• Flexibility to change codes or labels attached to text sections or add/remove codes assists in management of text and also supports analytical procedures.</li><li>• Opportunity to count some events and give an indication of prevalence.</li></ul>	<ul style="list-style-type: none"><li>• The formal/neat presentation of sections of text may encourage the researcher to become overly detached from the original context or the individuality of cases</li><li>• Researcher may also lose sight of their inherent effect upon the text generated.</li><li>• Temptation to increasingly quantify findings using the tools available.</li><li>• Researcher may remain ignorant to the narrative structure of the account and loose information about the flow/ordering that may hold meaning.</li><li>• Costs and training for use of the software.</li></ul>

Considering the potential benefits and risks, a software programme (i.e. Atlas.ti®) was used to assist with processing the large volume of interview accounts generated.

## 7.6 QUALITY CONTROL ISSUES IN QUALITATIVE RESEARCH

### 7.6.1 Objectivity, Validity and Reliability - a place in qualitative research?

The terms objectivity, validity and reliability are well established in quantitative study design and viewed as integral in enhancing quality (Polgar and Thomas, 2000). In contrast, the desirability and applicability of these constructs in qualitative, interpretive research is questionable and dependent upon the theoretical position of the



researcher (Grbich, 1999). There are no widely accepted criteria for assessing the degree of quality of a study or establishing how 'truthful' findings are and little attention is paid to the development of standards for critical review of qualitative research (Popay et al, 1998). Two extreme positions exist in relation to the application of traditional criteria to assess the quality of qualitative research. Some argue that the terms reliability, validity and objectivity can be used equally well in qualitative and quantitative approaches, with some modification of definition (Dingwall, 1992; Mason, 1996) but postmodernists argue that there no criteria that can be privileged nor applied (Popay et al, 1998). The middle ground is represented by those who aim to maintain a degree of objectivity throughout the inquiry, whilst acknowledging that value judgements are involved in qualitative research and are characteristic of its interpretive, dialectic basis (Guba and Lincoln, 1989; Kielhofner, 1982).

For this study it is considered that there are some criteria (e.g. validity) that are applicable to both qualitative and quantitative approaches, whilst acknowledging that a different type of knowledge is generated with qualitative approaches representing different perspectives of existing 'realities' (Denzin and Lincoln, 1994). Ultimately, there must be sensitivity to the quality of the research and strategies put in place so allowing the reader to evaluate whether the study accurately represents the phenomena being studied and to address questions of bias (Grbich, 1999). Lincoln and Guba (1985) studied the key traditional scientific criteria and developed four questions that are the basis of the quantitative criteria used to establish the trustworthiness of a study. These four questions (see Figure 7.6.1) are considered to be equally applicable in interpretive, qualitative research (Seale, 1999) and are therefore pertinent questions to ask of this study.

**Figure 7.6.1 Four Questions that can be asked of Any Research Study to Establish the Trustworthiness of the Study (Lincoln and Guba, 1985, p290)**

**Truth Value**

- How can one establish confidence in the 'truth' of the findings of a particular inquiry for the subjects (respondents) with whom, and the context in which, the inquiry was carried out?

**Applicability**

- How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects (respondents)?

**Consistency**

- How can one determine whether the findings of an inquiry would be repeated if the inquiry were replicated with the same (or similar) subjects (respondents) in the same or (similar) context?

**Neutrality**

- How can one establish the degree to which the findings of an inquiry are determined by the subjects (respondents) and conditions of the inquiry and not be the biases, motivations, interests or perspectives of the inquirer?

This study adopts a critical and rigorous approach to research design. Key rationale and standards to promote the quality of qualitative research were developed by integrating for the work of several qualitative researchers and are presented in Table 7.6.2.

### **7.6.2 Reflexivity**

Varying definitions and qualifications for reflexivity exist but it can be broadly characterised as that concerned with the researcher's self-awareness of his/her influence on the research process, appreciating their role as the main research tool (Holloway and Fulbrook, 2001). A reflexive researcher considers how they, themselves, may influence the research process and outcome based on his/her background, values, biases, perceptions and interests (Bryman, 2001; Ruby, 1980). A reflexive researcher does not deny that they influence research findings and conclusions, instead, they focus on developing a strategy and framework which offers a means for researcher and reader to assess the inherent subjectivity of the work. In this way, reflexivity is a key dimension of upholding research trustworthiness, it is assumed that bias is not eliminated through the researcher's commitment to be reflexive; it is accounted for rather than ignored (Malterud, 2001b). Being reflexive influences many stages of the research process, explication of the researchers preconceptions, implementing the use of a field journal and techniques used in analysing findings (e.g. looking for competing explanations, Malterud, 2001b). Reflexivity is embedded within this study's methodology.

**Table 7.6.2 Key Standards and Corresponding Strategies to Support the Generation of Quality, Qualitative Inquiry into Pain Meanings (developed from - Altheide and Johnson; 1994; Dingwall; 1992; Guba 1981; Popay et al, 1998; Ritchie and Spencer, 1994; Seale, 1999).**

Standards	Corresponding Strategies for Implementation
Privileging the subjective view of both the patient and rheumatologist and the way meanings are ascribed.	<ul style="list-style-type: none"> <li>• Study aims are founded upon participants' perspectives and processes supporting meanings.</li> </ul>
Incorporate flexibility in design to respond to accounts generated, pursue uniqueness and adapt.	<ul style="list-style-type: none"> <li>• Flexible interview technique aimed at generating diverse and in-depth accounts.</li> <li>• Change questions to pursue new lines of thought or emerging theories/ideas.</li> </ul>
Maximising contextual variation to observe change in meaning/s.	<ul style="list-style-type: none"> <li>• At interview - talk about different social contexts, times, experiences.</li> <li>• Diversity within the sample group e.g. demographic variability.</li> </ul>
Evidence of theoretical and/or purposeful sampling to actively pursue individuals who may further illuminate understanding.	<ul style="list-style-type: none"> <li>• Use of purposive and theoretical sampling.</li> <li>• Sample until the point of theoretical saturation (i.e. themes are not refined by further sampling).</li> </ul>
Evidence of adequate description i.e. enough detail to allow the reader to make judgement of what is presented.	<ul style="list-style-type: none"> <li>• Clear presentation of what was done and why.</li> <li>• Coding diary for code and theme development.</li> <li>• Use of thick-description i.e. give context to the experience.</li> <li>• Use quotes that enrich and support synopses presented.</li> <li>• Judicious use of counting in presentation of the findings.</li> </ul>
Evidence of the quality of the findings i.e. show evidence of using varied sources of knowledge to compare and contrast with what is developed in findings.	<ul style="list-style-type: none"> <li>• Display negative cases that 'do not fit' with emerging theories/themes.</li> <li>• Peer review of analysis.</li> <li>• Member checks ( i.e. respondent validation).</li> </ul>
Evidence of awareness of how the researcher could have shaped the findings and evidence of transparency in interaction with research processes.	<ul style="list-style-type: none"> <li>• Peer review of analysis and interpretations.</li> <li>• Reflexive accounting of researcher influence from generation to analysis of accounts (e.g. reflexive notes in a research diary).</li> </ul>
Clarity in the presentation of the evolution of theoretical/conceptual thinking.	<ul style="list-style-type: none"> <li>• Show boundaries in accounting for how the findings move from respondents' words, to descriptions to presentation of inter-relations or abstractions made.</li> <li>• Use of memos to track interpretations.</li> </ul>
Enable the reader to judge typicality i.e. is it appropriate that such claims have been made in relation to generalising findings to other groups or knowledge domains?	<ul style="list-style-type: none"> <li>• Accurate and detailed description of groups and context and recruitment.</li> <li>• Involve experts in the evaluation of the findings and judge the usefulness of the knowledge.</li> </ul>

### **7.6.3 Reliability and Reproducibility in Qualitative Research**

Within constructionists' framework multiple realities exist and study replication is therefore not a primary aim. Instead the researcher is required to present an inquiry which is coherent, complete and fully explored, allowing the reader to fully comprehend what was done, as well as assess its worth (Grbich, 1999). This does not detract from the necessity of qualitative methods and research practice to be accurate, honest and carefully conducted (Mason, 1996). The incorporation of peer review of methodological processes, coding and interpretations is valid basis for facilitating study credibility rather than attempts to show that the study could be repeated elsewhere and/or with other respondents to produce exactly the same findings.

### **7.6.4 Generalisability and Qualitative Research**

Generalisability is related to the ability of the researcher or others applying study findings to another groups, populations or those in settings other than those studied. In principle, research should produce information that can be shared and applied beyond the immediate context of the study; however, this is dependent upon the assumptions of the research question and the appropriateness of the sampling strategies used (Malterud, 2001b). In qualitative research, generalisability is often based on the assumption that the theory or explanations developed may be useful in making sense of similar situations but is not designed to enable probabilistic generalisations to be made to a population (Maxwell, 1992; Popay et al, 1998). Patton (1990) emphasised that the function of qualitative work is in providing useful information that is generally focused on a particular context or issue being evaluated/explored. This is the position adopted in this study. To enable the transference of findings to similar settings or to make questions raised applicable to other settings is dependent upon the similarity/difference to the original setting/sample. It follows, therefore, that rich description of the sample, typicality/atypically and context are required (Mason, 1996). Barbour (2000, p158) suggests that findings can also be 'theoretically generalizable'. This refers to the usefulness of the explanatory frameworks or explanations developed from the research, which may have an application outwith the immediate context of the study.

### **7.6.5 Purposive Sampling for Diversity, Trustworthiness and Usefulness**

Sampling is a process used for selecting individuals for inclusion in a study. The qualitative researcher aims to identify groups or subjects who have characteristics relevant to the study of the phenomena and selection is

influenced by an attempt to explore the phenomena fully, to access as wide a variety of experiences and perspectives on the phenomena in question (Reed and Procter, 1996). Sampling often uses non-probability techniques and the focus is on choosing cases that will yield rich, complex findings e.g. respondents who are likely to present the range of issues that are central to the study purpose (Patton, 1990). Maximum variation or non-representative 'stratified' sampling is a purposive sampling technique where the researcher selects individuals who will provide the best representation of the research questions definable aspects (Trost, 1986). This study uses this strategy by drawing upon the literature which supports that a patient sample with varied age, gender, sociodemographic variables etc. is likely to provide a diversity of pain accounts (see Section 3.6). Similarly, for rheumatologists, stratified sampling is supported by the literature suggesting that selecting rheumatologists with varied age, gender, hospital location site etc. may give a more comprehensive coverage of the potentially available pain accounts (see Section 5.6).

Flexibility in the sampling strategy is also required where a particular phenomenon emerges from the findings and exhibits novel and diverse features in which case more individuals, of say, a particular age group, may be pursued i.e. theoretical sampling (Strauss and Corbin, 1998). Individuals are selected on the basis that they will advance the analytic goal rather than enhance the transference of findings to the greater population (Sandelowski, 1995). Similar to the purposive nature of sampling for a qualitative study, sample size is dependent upon the study purpose and there are no rules guiding sample size in qualitative studies (Patton, 1990). However, Patton (1990, p184) suggests that decisions about the number of subjects to be interviewed are influenced by several factors, as follows:

1. How many will be needed to make the study credible given the depth and purpose of the study?
2. What can be done in the given time and with the resources available?
3. As findings are gathered, what is the quality of the information gathered per interview?

## **7.7 ETHICAL ISSUES**

Mason (1996) suggests researchers should develop an ethical practice which can respond dynamically to challenges as and when they present in qualitative researching. Ethical codes and guidelines for research practice are useful in that they have operationalised some major ethical concerns (Murphy et al, 1998, p148), however, these codes are limited in their application, only covering the 'big issues' related to the use of covert methods,

exploitation or damage (Mason, 1996). Ethics committees may grant approval for a project but this would only be related to the intent of the research proposal and not the research actions which follow; the nature of qualitative inquiry makes it impossible to foresee issues that may arise with time and in varied contexts (Smith, 1992). The key ethical issues in research can be categorised as follows (Punch, 1994):

- Potential harm to participants;
- Provision of informed consent;
- Respect for privacy and confidentiality;
- Issues related to deception.

### **7.7.1 Harm**

Harm of a subject involved in study of any form, whether physical, mental or emotional is unacceptable. The potential harm or risk to a participant in qualitative studies may be regarded as less of an issue than biomedical, experimental studies (Murphy et al, 1998). However, there is risk of psychological harm (especially to patients) e.g. anxiety or embarrassment during interview or at the stage of publication of the work (Kelman, 1982). May (1989) outlines ethical issues related to interviewing suggesting the provision of support information for patients, awareness of the risks of misunderstandings arising during interactions and the likelihood of having to make compromises between the goals of the research and the needs of the informant. The researcher must also foresee the potential harm not only to those whom are researched (whose identity may be well concealed), but also to those about whom generalisations may be made e.g. Scottish consultant rheumatologists (Miles and Huberman, 1994).

### **7.7.2 Informed Consent**

Informed consent is a complex issue, an important means through which informants' rights can be protected. Consent should be voluntary but is complicated by issues of the relatively greater power of the researcher and the influence this may bring to bear (Murphy et al, 1998). Respondents must be judged competent to give informed consent and potential volunteers must be provided with a full and understandable explanation about intended study and their role in it and made aware of any potential risks of publication at a later date. The developmental

and flexible nature of qualitative inquiry may require the researcher to re-negotiate informed consent at a later date if the research progresses in unforeseen ways (Mason, 1996).

### **7.7.3 Privacy, Anonymity and Confidentiality**

The nature of qualitative work emphasises personal detail and context within accounts i.e. gathering detailed and information rich data, often tied to details such as age, social circumstances etc. This may challenge attempts to maintain privacy, confidentiality and anonymity (Mason, 1996). The researcher must protect the anonymity of respondents and keep accounts confidential, restricting access to records and considering the security of accounts and findings at all stages of the study (Miles and Huberman, 1994). Concealing identities, locations and places within transcripts must also be considered in the published form, being cognisant that individuals or an institution may be recognised. These latter points are especially relevant when sampling from a discrete group e.g. consultant rheumatologists in Scotland. Such recognition may do harm to an individual's or an institution's reputation or harm the individual's psychological wellbeing (Lipson, 1997).

### **7.7.4 Deception**

There is a mutual trust between the researcher and society and deception is neither desirable nor agreeable (Bryman, 2001). Arguably there are less grounds for accusations of being deceptive in a study which is overt in its methods and its aims; however, it is also true that provision of a complete account of what the research is about is rarely given to the subjects. The aim has to be to maximise clarity regarding the intentions of the researcher without compromising the aims, which often rely upon the informants giving as uncensored an opinion as is possible within the context of the interview period (Smith, 1992).

## **7.8 SUMMARY AND CONCLUSIONS**

Valuing knowledge of patients' and rheumatologists' subjective meanings related to the phenomenon of pain and an interest in understanding human interpretation and action is consistent with interpretive research paradigms founded in an ontological perspective of constructionism. Selecting a pragmatic and interpretive qualitative approach to the study of pain meanings enables the researcher to benefit from the influence of several traditional

interpretive paradigms and their respective methodological strategies. This also enables broadening of the interpretive opportunities and theoretical sensitivities in analysis, whilst maintaining flexibility of design to best accommodate the research questions and aims. Semi-structured interviews can offer insight into respondents' experiences and how they make sense of phenomena e.g. pain. However, the researcher must be cognisant of how he/she may have shaped the co-constructed accounts. Account analyses may reveal something of the essence of a phenomenon but must also address how other factors (e.g. context) may shape what is said. Although controversy exists regarding the applicability of traditional, positivist research criteria to qualitative inquiry, there is consensus that the truth-value (or trustworthiness) of the study must be upheld and clearly demonstrated to produce findings that are useful and relevant. A critical, reflexive and rigorous approach to study design and conduct is proposed for this study. It is not the intention of the study to generalise findings to populations and contexts not typical of those explored in the study. This study is committed to safeguarding respondents' privacy, confidentiality and wellbeing and providing full and understandable explanations about the research and their role in the research.



## 8 CHAPTER EIGHT - METHODS

### 8.1 INTRODUCTION

This chapter is presented in two sections. Section 1 is an overview of the early exploratory stages of the inquiry and covers the key-informant discussions with patients and rheumatologists. These discussions confirmed the relevance of the main research questions which, in turn, formed the basis of the interview guides used in the study. Here, it should be noted, that motivation for early consultation with patients and rheumatologists arose from the determination that the study should remain grounded in the current issues and concerns of patients - thus addressing expectations of what would be the most valuable outcome of the study.

Section 2 of the chapter (from Section 8.3 onwards) outlines what was done in carrying out the study. It should be noted, however, that although processes and procedures are listed sequentially, the nature of the work was not sequential but was in fact iterative, cyclical and inter-connected. Preceding sections 1 and 2 of the chapter, the study aims and research questions are re-stated (Figure 8.1) and this restatement is followed by a flow-diagram (Figure 8.1.1) which shows how the stages of the enquiry affect each other in a non-linear manner.

**Figure 8.1 Re-statement of the Main Research Question and Aims**

#### Main Research Question

- What is the meaning of pain in rheumatoid arthritis from the perspective of both patients with the condition and of rheumatologists working with such patients?

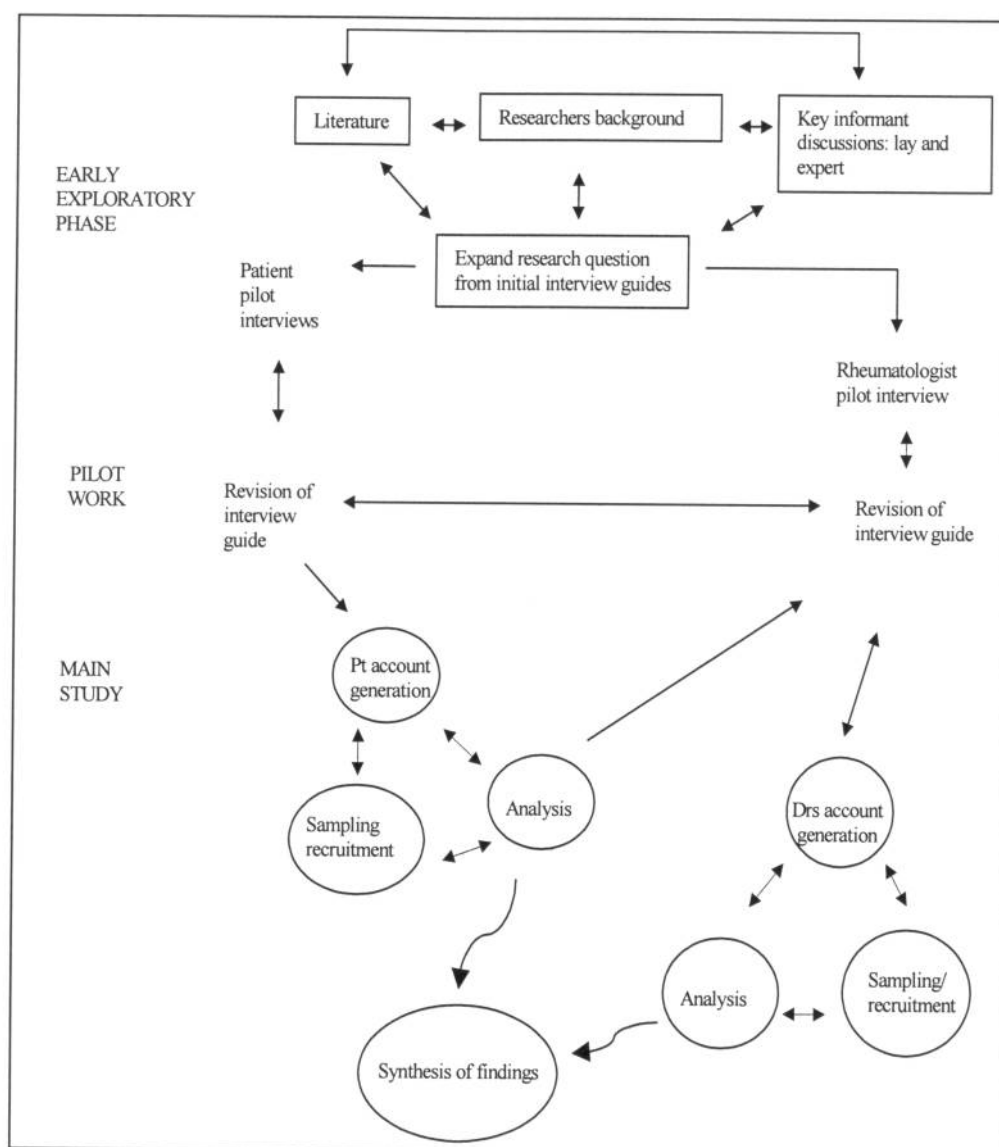
#### Main Research Aim

- To explore the meanings of pain in rheumatoid arthritis from the perspective of patient and rheumatologist, where 'meaning' encompasses the perspective of the participant.

#### Sub-Aims

- To describe what meaning/s related to pain in RA are offered by participants, through talk, which reflects how they perceive pain in RA.
- To explore how these pain meanings, related to pain phenomena in RA, are constructed.
- To compare and contrast patients' and rheumatologists' conceptions of pain in RA.
- To discuss the implications of all of the above findings with regard to management of pain and its consequences in RA.

Figure 8.1.1 Overview of the Stages of Development of the Research



## 8.2 THE EARLY EXPLORATORY PHASE

### 8.2.1 Introduction

Literature on RA and chronic pain provides justification for the need to expand knowledge about patients' and doctors' pain meanings in RA. However, the researcher wanted affirmation from those most knowledgeable in the field that answers to the types of questions formulated would be accepted as being of value to patient care. Consulting key patient and medical experts in the early phases of the study enabled identification of specific pain

related concerns which should be addressed in initial research questions and respective interview guides. Careful design of specific 'mini-research questions' was considered a necessary precursor to deep understanding of particular pain dimensions. It was thought that open-ended, non-structured 'depth' interviews would fail as an approach to generate 'deep' understanding of particular pain dimensions. Collaboration with experts in the field of patient care/support and education in RA (i.e. lay support leaders and healthcare experts) was useful in making contacts for recruitment, peer review of interpretations and findings and creating routes for dissemination for the study findings.

### **8.2.2 Study Location and Collaboration**

The researcher was based at Queen Margaret University College Edinburgh. Contact with a regional Arthritis Care group co-ordinator and the lead, lay educator was established. Arthritis Care is a patient-led, national organisation promoting patient empowerment through increased knowledge of the condition and its management. Medical contacts were established with rheumatologists at a regional NHS secondary care facility for rheumatological care. This culminated in identification of a rheumatologist interested in the study and willing to provide time for discussion and advice through different stages of the inquiry. As a contrast to this hospital-based rheumatology service, a Primary Care based rheumatology service in a different region was contacted and a link established with the lead rheumatologist at this site for key informant discussions, recruitment and dissemination of findings.

### **8.2.3 Researcher's Background and Observations**

The background, values and interests of the researcher play a part in colouring the qualitative inquiry and should be made apparent (Bryman, 2001). I am a Chartered Physiotherapist, qualified for over 12 years and specialise in musculoskeletal physiotherapy. I have worked primarily within the NHS. I have worked with patients with RA and with rheumatologists, primarily within secondary care sited physiotherapy outpatient departments. I have also been involved in the development and running of multidisciplinary educational programmes for those with RA (1996-1998). At the time of this study I was not working within the NHS but was engaged in full-time researching.

Two observations made during clinical work with patients with RA stimulated my interest in this group and in the subject of pain. Firstly, I noticed that there was a range of responses to the disease, many patients appearing stoical in the face of significant daily difficulties and pain experiences, uncomplaining and undemanding, others appearing less stoical and all variations between. The second observation related to the frequency with which the patient's perspective of the presenting problem did not always match mine. These observed phenomena led directly to my interest in understanding more about what patients and health professionals think about the complex phenomenon of pain in RA.

## **8.2.4 Key Informant Discussions with Patients**

The aim of the key informant discussions with patients was to get a 'feel' for the area of discussion and to find out what the issues regarding pain in RA were. Then, from respondents' point of view, to gauge patients' views on study aims and research questions and their perception of the relevance of potential findings. Additionally, discussions were used to elicit talk of personal experiences of pain and its present and future consequences; thus, gaining an impression of the pain issues in RA and an idea of how talk about RA/pain in RA might proceed.

### **8.2.4.1 Sample group**

Individuals were selected in view of their exemplary experience and knowledge of RA/chronic pain and therefore with the potential to inform the study about patients' concerns/experiences. Some had a medical background and were able to reflect upon both giving therapy, advice, support and/or receiving it. Recruiting was possible via contacts with Arthritis Care, an advert placed in the Arthritis Care News, contacts at the University College and having attended a Patient Partners meeting (see Appendix 1.1). Table 8.2.4 outlines the key informants' profiles.

**Table 8.2.4 Sample Group for Patient Key Informant Discussions**

Code name and Occupation	Personal Profile
KI 1 Arthritis Care Educational Co-ordinator	Female Age 40 Diagnosed with RA: 25 years Former allied healthcare professional Extensive experience of educating patients and experts on aspects of illness related to RA
KI 2 Post-graduate researcher (knowledge and understanding of qualitative methodologies)	Female Age 30 Diagnosed with RA: 15 years Family history of RA Extensive experience of hospital interactions at varied NHS centres throughout life as an in-patient and out-patient
KI 3 Challenging Arthritis Leader	Female Age: 51 Diagnosed with RA: 8 years Retired nurse Experience of depression, in-patient and out-patient treatment and delivering and receiving patient education
KI 4 Medically retired	Female Age: 53 Diagnosed with RA: 14 years Medically retired senior NHS manager (dealt with patient complaints) Opted for non-conventional, non-NHS treatment for RA (intra-dermal injections of food intolerance medication)
KI 5 Patient-Partner co-ordinator (educating patient partners and medical experts on examination techniques in arthritis)	Female Age: 29 Diagnosed with SLE*: 13 years Extensive experience of consultations, chronic illness, teaching rheumatologists and expert-patients  *SLE - Systemic Lupus Erythematosus: similar to RA in that it is also associated with chronic pain, fatigue and symptomatic 'flares'

### 8.2.4.2 Methods

Key informant discussions are characteristically of a conversational manner, loosely structured and often lengthy (Werner and Schoepfle, 1987). This reflected the key informant discussions conducted in this study. A topic guide was used to ensure broad topics were covered e.g. experiences of living with chronic pain, medical care, understanding of pain and respondents' view of other's knowledge of pain in RA. Discussion commonly followed respondent's experiences and ideas. Discussions with each participant lasted on average 2-4 hours,

some being conducted over several sessions. Half of the discussions were tape recorded and in all cases notes were made both at the time of the interview and when reviewing the tapes.

#### **8.2.4.3 Analysis of accounts**

Descriptive analysis of the content and nature of the discussion topics was carried out. Working inductively from the notes taken, the main pain-topics/issues highlighted by each respondent were grouped, compared/contrasted and described using a basic thematic analysis approach (Boyatzis, 1998). There was no attempt to inter-connect the topics at this stage, the aim was to produce a descriptive list of the main concerns/issues, understanding, experiences and/or consequences of pain in RA.

#### **8.2.4.4 Findings**

The best method of eliciting free-flowing and 'comfortable' pain accounts was through the respondent being asked open questions about their own experiences to induce a narrative form e.g. how did it all start? Questions from the interviewer (Stella Howden) about pain sensation repeatedly blocked the flow of conversation; the primary talk of pain being related to the consequences for self and family. The researcher occasionally returned to a closed question format when talking about sensory-discriminative topics, possibly arising from her background in physiotherapy where pain talk is often related to diagnostics. See Table 8.2.4.1 for the main descriptive findings.

#### **8.2.4.5 Conclusions**

Pain was considered a significant problem in RA, impacting upon all domains of life for those with RA and this supports literature findings. The findings supported the need to explore both patients' and rheumatologists' conception of pain, the rheumatologist was clearly identified as a significant figure in patients' lives; being viewed as powerful, influential and crucial in RA management. Patients focused on issues surrounding consultations in their pain accounts e.g. problems expressing pain, identifying this as an important area for exploration. Exploration into patients' understanding of pain in RA revealed varied knowledge that was closely related to their understanding of the disease, therefore beliefs about disease must be explored as thoroughly as pain. Other areas of importance to patients requiring inclusion in study questions were, distinction between flare

and non-flare, medical management issues (drug usage), clinical assessment experiences (e.g. talk about pain) and the breadth of consequences of pain (personal and wider e.g. family).

**Table 8.2.4.1 Descriptive Findings from the Key Informant Discussions with Patients**

Topic Area	Nature of the Account
Pain and RA	<ul style="list-style-type: none"> <li>Closely associating pain with the underlying disease (varied understanding of the mechanisms).</li> </ul>
Influencing Pain Beliefs	<ul style="list-style-type: none"> <li>Strong reflection upon their bodily or personal experiences shaping their views.</li> <li>Clear distinction between different pain experiences - flare and non-flare.</li> </ul>
Impact of Pain in RA	<ul style="list-style-type: none"> <li>Consequences of pain – impact on the family; significant emotional and physical toll.</li> <li>Pain is a significant part of life with RA and shapes the illness experience.</li> </ul>
Role of Rheumatologist	<ul style="list-style-type: none"> <li>The rheumatologist is considered to be a key figure in the management of RA, the main provider of knowledge, advice and treatment.</li> </ul>
Pain Reporting	<ul style="list-style-type: none"> <li>The relationship with the rheumatologist is important and valued and may influence behaviour of the patient regarding pain talk.</li> <li>Patient sees expression of pain at clinic as problematic, difficulty in being understood.</li> </ul>
Medical management of pain in RA	<ul style="list-style-type: none"> <li>Medical management of RA - strong feelings and views regarding medications for treatment of RA and pain (i.e. concerns about adverse effects).</li> </ul>
Self-management of pain in RA	<ul style="list-style-type: none"> <li>Variable knowledge about how to best manage pain independently or using medications.</li> </ul>
Consultations and Pain	<ul style="list-style-type: none"> <li>Variable experiences of interactions about pain due to different environments/context (e.g. busy clinics) and the relationship with the rheumatologist.</li> </ul>
Potential Value of the Study	<ul style="list-style-type: none"> <li>Suggest that the findings may help health professionals understand what patients experience.</li> <li>Suggest that it would be valuable to identify what patients know and don't know about pain in RA.</li> </ul>

## 8.2.5 Key Informant Discussions with Consultant Rheumatologists

### 8.2.5.1 Aims

As per patient discussions, the aim here was to get an impression of rheumatologists' perception of the value of the study, at the same time gaining an early view of their understanding and perception of the nature and problem of pain in RA. Discussions also included exploration of how they perceived their roles and responsibilities in management of pain in RA.

### 8.2.5.2 Sample

Two consultant rheumatologists in two different regions of Scotland agreed to participate in the informal discussions. See Table 8.2.5.

**Table 8.2.5 Sample Group for Rheumatologist Key Informant Discussions**

Occupation	Personal Profile
Dr KI 1 Consultant rheumatologist in NHS Trust (University teaching hospital)	Male Age: 38 years Years specialising in rheumatology: 10 Interest in the study but strong background in scientific, quantitative research, little knowledge /understanding of qualitative approaches
Dr KI 2 Consultant rheumatologist within a Primary Care Trust (with a domiciliary multidisciplinary team service)	Female Age: 43 years Years specialising in rheumatology: 9 Interest in patient perspectives and patient-centred care and qualitative inquiry, had conducted work in gathering patient views regarding rheumatology services

### 8.2.5.3 Methods and analysis

The same methods/analysis as used for the patient discussions were used for the rheumatologists. Each consultant was involved in two discussion sessions of approximately 1½ hours and had been sent copies of the research proposal before the meeting in order to facilitate discussions.



#### 8.2.5.4 Findings

The rheumatologists appeared comfortable with direct questioning and responded quickly and articulately. They provided the most revealing, evaluative narratives when recounting patient scenarios or cases, which was noted as a potentially useful future form of questioning/probing. See Table 8.2.5.1 for findings.

**Table 8.2.5.1 Key Descriptive Findings from the Key Informant Discussions with Rheumatologists**

Topic Area	Nature of the Account
Pain and RA	<ul style="list-style-type: none"><li>• Variable biasing of the mechanisms and processes that support pain (e.g. biomedical and psychosocial models of pain).</li></ul>
Impact of Pain	<ul style="list-style-type: none"><li>• Identify pain as a significant burden for the patient with RA at all stages of the illness.</li></ul>
Managing pain in RA and 'typing' patients	<ul style="list-style-type: none"><li>• Identify pain as a problematic symptom to treat in a significant proportion of cases (time consuming) and make distinction between those who can 'cope' and those who cannot.</li><li>• Giving case examples illuminating how they evaluate pain.</li></ul>
Patient self-management in RA	<ul style="list-style-type: none"><li>• Identify that patients have a significant role to play in their own self-management of pain.</li></ul>
Resources and pain management	<ul style="list-style-type: none"><li>• Identify issues related to the inadequacy of resources e.g. time available to deal with patients in pain.</li></ul>
Potential value of the study	<ul style="list-style-type: none"><li>• Report that results of this study would be useful in informing health professionals of the patient experience and knowledge status.</li><li>• Interested to know what other their colleagues think about pain in RA and how they deal with it.</li></ul>

#### 8.2.5.5 Conclusions

Again, the interest in potential study findings appeared positive and was deemed an important study topic in RA (neither consultant was aware of any other similar research). A concern raised by one participant was that the study would engage in 'doctor bashing' or produce 'yet another pain questionnaire' that would not be clinically useful. Fear of the study assuming an antagonistic approach towards medical practice is not without foundation, this tendency in qualitative research on chronic illness has been noted before (Gerhardt, 1990). Practical and basic information was viewed as being more valuable e.g. are rheumatologists attending to pain in RA? Several key topics identified by the participants paralleled the patients' findings i.e. the negative impact of pain on life.

Particular to consultants' discussions was the classification of 'types' of patient response to pain. This could be explored through case examples elicited in interview, which could to be useful in eliciting evaluative narratives. The incorporation of contextual issues (e.g. time available for consultations) in relation to pain management appears an important inclusion for exploration. Incorporating a clinical frame of reference (e.g. relating to issues of clinic interactions and pain interventions) within the interview guide and adopting an attitude seeking to understand the functions, as well as the dysfunctions, of related pain meanings may assist attempts to address these issues.

## 8.2.6 Development of the 'Mini-Research Questions' to Address Aims

Integrating the findings from all the key informant discussions with the original aims (shaped by existing literature), a series of patient and rheumatologist 'mini-research questions' were developed. These served as the basis for interview guide formation ensuring that account generation would be relevant to the concerns of patients and rheumatologists and to the gaps identified in the literature. Tables 8.2.6a and 8.2.6b list the patient and rheumatologist 'mini-research questions' respectively.

**Table 8.2.6a Mini-research Questions to Address the Research Aims Regarding Patients' Perceptions of Pain in RA**

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### Main Research Question for Patients

- What is the meaning of pain in RA: the perspectives of patients' with rheumatoid arthritis?
- 

Key mini-research questions to inform the interview guide development and help to answer the main question, for the patient sample:

1. What are the patients' perspectives or understandings of pain, and RA, as well as pain in RA? I.e. how is pain explained and described in relation to the disease?
  2. How do patients with RA perceive the impact or influence of their illness/pain on their lives? I.e. what are the consequences for self, family and others?
  3. What are patients' perspectives on the treatment and/or management of RA/pain? I.e. how do patients deal with pain or cope with its consequences? Considering self-management, medical management, drugs etc.
  4. From the patients' perspective, what are the roles of the rheumatologist in their care (e.g. professionally and clinically)? Considering assessment, evaluation, prescription of medication, advice, empathy etc.
-

**Table 8.2.6b Mini-research Questions to Address the Research Aims Regarding Rheumatologists'**

**Perceptions of Pain in RA**

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Main Research Question for Rheumatologists

- What is the meaning of pain in RA: the perspectives of rheumatologists?
- 

Key-mini-research questions to inform the interview guide development which help to answer the main question, for the rheumatologists sample:

1. What are the rheumatologists' perspectives or understandings of pain and RA and pain in RA, the disease and the pain experience?
  2. How do rheumatologists perceive the impact or influence of RA/pain on patients' lives? Considering patient, patient's family etc.
  3. What are rheumatologists' perspectives on the management and treatment of RA/pain? Considering self-management, medical-management and others.
  4. How do rheumatologists view their role in caring for the patient with RA (professionally and clinically)? Considering assessment, evaluation, prescription of medication, advice etc.
- 

These questions were further sub-divided and transformed into potential interview question format (see Appendix 8) and further refined through pilot interview processes and continued to be modified as analysis and account generation progressed to expand understanding of pain meanings.

## **8.3 SUBJECTS**

### **8.3.1 Patients with Rheumatoid Arthritis: inclusion and exclusion criteria**

Patients were recruited from across two central regions of Scotland. Inclusion and exclusion criteria are listed in Table 8.3.1. Diagnosis was self-reported; the accuracy of self-reported diagnosis of RA is documented as 96% for a community based group (Barlow et al, 1998). As the study of pain meanings is complex it was decided that respondents should be from a homogeneous cultural background i.e. there was no cross-cultural dimension.

**Table 8.3.1 Inclusion and Exclusion Criteria for Patient Participation in the Current Study**

---

Inclusion and Exclusion Criteria

---

Inclusion Criteria

- over 16 years of age
- diagnosed with RA for at least one year or longer (self-reported)
- able to read, write, hear and speak English
- able to give informed consent
- attend a NHS rheumatology out-patient department at least once a year for review
- currently experience pain (of any degree) related to RA
- English as a first language
- Caucasian, born in the UK

Exclusion Criteria

- have other concurrent, painful or disabling condition/s
  - are currently involved in other RA related research (an ethical consideration for patients, who may be influenced by trial related testing and examination procedures)
- 

### **8.3.2 Interviewee Profiles for Patients**

Interviewee profiles were generated for all respondents. This information was collected for its potential relevance to the nature of pain accounts and was required to inform the analysis, providing additional biographical detail that may be insightful for developing explanations and understanding. It also enabled grouping of patients for comparison around specific factors e.g. accounts of those with a medical background and those without.

Details collected for patients included demographic information, sex, age, duration of disease, occupational status, educational background, social circumstances, medications prescribed and taken, details of any other health problems, family history of RA or friends with RA, background in health or medicine/caring, attendance at arthritis support groups or educational groups, number of visits to the rheumatologist per year, the number of years attending their current rheumatologist and the sex of the rheumatologist they attend. Patients were asked to self-rate their perceived degree of global functional status using the American College of Rheumatology classification scheme (Hochberg et al, 1992; see Appendix 9.1). This four point ordinal scale was used a simple and rough indicator of patients' perceived degree of disability paralleling as a crude indicator of disease severity. Patients' postcode was used to enable calculation of Carstairs's deprivation scores (see Appendix 9.2) a recognised predictor of health status (Carstairs and Morris, 1991).

### 8.3.3 Patient Recruitment

Recruitment was sited in two regions where the number of patients with RA in each region is estimated at 5, 214 and 2, 314 respectively (Gray and Muirie, 2002). The two regions were used to increase the diversity of socio-economic background and exposure of patients to diverse types of service provision. Each region is served by hospital based rheumatology services, in addition the Steeltown (pseudonym) regional service also operates a community based multidisciplinary team to support the patients at home where necessary. Patients were recruited using multiple methods:

- Posters and leaflets were displayed in hospital out-patient waiting areas at three hospital sites;
- Rheumatology nurse practitioners gave leaflets to patients for them to consider at clinic appointments;
- Leaflets distributed at Arthritis Care support groups and Challenging Arthritis groups;
- Leaflets were left within the rheumatology ward for those being discharged thus targeting those who may be more severely affected by RA.

The significant benefits of rheumatology nurse practitioners handing leaflets to patients were realised, as they were able to target those known to be eligible for inclusion. They advised patients that the study was independent of the hospital and would not affect treatment. Patients were advised to return the pre-paid response slip from the recruitment letter if they were interested in participating or wanted further information. In reply, they were sent an information sheet and an example of a consent form and were advised there would be a follow-up phone call to answer any further questions and ask if they would like to participate. At the time of the follow up call, eligibility for participation was re-checked and, where the patient wanted to participate, a date and time convenient to the patient was scheduled for interview at the patient's home.

### 8.3.4 Sampling - the patient group

The initial sampling strategy was purposive, aiming to include those typical of a population of adults attending rheumatology clinic with established RA, whilst simultaneously generating a group with a diversity of pain experiences and likely to have diverse pain accounts. The literature suggested that important characteristics were: sex, age, socio-demographic and socio-economic status, educational background, disease duration, location of treatment, marital status, social support at home and stages of illness (see Section 3.6). An initial quota target list of 20 was generated based upon similar work by Johansson et al (1999). Table 8.3.4 shows the initial quota list.

**Table 8.3.4 Initial Quota Target List for Stratified Sampling of Patients with RA**

---

Aim to Include within the Sample Group of Patients

---

- at least six people from each of the two regions identified for recruitment
  - at least three people in each of the three age groups (18-40, 40-60 and over 60)
  - at least four people in each of the self-rating severity groups II and III (ACR Functional Status Score, see Appendix 9.1)
  - at least five people in each occupational category (professional and semi-skilled)
  - at least three people in each category for duration of the disease ( $\leq 5$  yrs or  $\geq 5$  yrs  $\leq 10$  yrs or  $\geq 10$  yrs)
  - at least eight women, ensuring that there are two in each category above (i.e. disease duration)
  - at least eight men, ensuring that there are two in each category of disease duration
  - at least ten people who are married
  - at least five people who are single or living alone
  - at least five people who are working
  - at least one person within each category of the Carstairs's deprivation category (see Appendix 9.2)
- 

In later stages, when data analysis and sampling were concurrent, a theoretical sampling strategy was used to specifically enable development of themes that were emergent (Strauss and Corbin, 1990). Patients with specific characteristics were sought-out where they may be able to help clarify themes or seeking greater understanding of a particular dimension of the phenomenon. Rheumatology nurses were able to assist in this process by distributing leaflets selectively. Sampling continued over eight months.

### **8.3.5 Rheumatologists: inclusion and exclusion criteria**

Rheumatologists were recruited from throughout Scotland. Initial plans to sample those at different stages of training were obstructed by difficulty in recruiting non-consultant grades who were 'too busy' to participate due to examination commitments. Based on this and, since patients most value consultant level rheumatologists for advice and guidance (from key informant discussions) it was decided to exclusively recruit consultant grade only. [At the time of the study there were approximately 32 whole time equivalent consultant rheumatologists in Scotland.] See Table 8.3.5 for inclusion criteria.

**Table 8.3.5 Inclusion Criteria for Rheumatologist Participation in the Current Study**

Inclusion Criteria
<ul style="list-style-type: none"><li>• able to read, write, hear and speak English</li><li>• able to give informed consent</li><li>• work in a NHS hospital out-patient clinics</li><li>• regularly (at least fortnightly) engage in clinical management of adults with RA</li><li>• English as a first language</li><li>• consultant rheumatologist grade</li></ul>

### **8.3.6 Interviewee Profiles for Rheumatologists**

Data collected regarding rheumatologists included: age, gender, region of workplace, years specialising in rheumatology, any friends or family with RA and other roles or special interests e.g. clinical tutor.

### **8.3.7 Rheumatologist Recruitment**

Letters were sent to consultants and followed up by a phone call within two weeks of posting to ask if they were interested in participation and also to answer any questions about the study. Where interest was noted further information and a sample consent form was mailed out and a time/date arranged for interview (all were conducted at the doctor's place of work).

### **8.3.8 Sampling - the rheumatologist group**

Literature supported sampling rheumatologists with varied: age, gender, length of experience, working with varied types of patients, varied practice setting and site (see Section 5.6). A quota target list for sampling consultants was based upon a hypothetical sample size of 10, assuming that all medically trained experts with the same speciality are more likely to present homogenous pain accounts than patients who have widely different backgrounds and experiences of RA. There were no comparable studies to guide sample numbers and 10 was taken as an educated guess incorporating estimation of the number of professionals available within the sample population. See Table 8.3.8 for the sample quota list.

**Table 8.3.8 Initial Quota Target List for Stratified Sampling of Consultant Rheumatologists**

---

Aim to Include within the Sample Group of Rheumatologists

---

- at least 3 females
  - at least one within each age category: 30s, 40s, 50s and 60s
  - at least two within each category of years specialising in rheumatology:  $\leq 10$  years or  $\geq 10$  years  $\leq 15$  years or  $\geq 20$  years
  - at least 3 working within the most affluent regions of Scotland
  - at least 3 working within the least affluent regions of Scotland
  - at least 3 working in Regional Teaching hospitals
  - at least 3 working within District General hospitals
- 

### **8.3.9 Sample Size for Patient and Rheumatologist Groups**

Sample size was not predetermined for either sample group and was dependent upon fulfilling the proposed aim of fully exploring the themes and being sufficient to support credibility attendant on the aims of the study, to fulfil a sense of completeness of exploration (within the constraints of resources of time to collect and process findings; Patton, 1990, p184). The aim was to sample patients/doctors until the point of theoretical saturation (where sampling more respondents does not further refine themes; Strauss and Corbin, 1998).

## **8.4 ETHICS**

### **8.4.1 Ethical Approval**

Ethical approval for the study was obtained from The Research Degrees Committee (Queen Margaret University College, Edinburgh) and the appropriate regional ethics committees. Approval for subject recruitment was received from relevant NHS Trusts.

### **8.4.2 Informed Consent**

All potential interviewees were sent information sheets, a full and understandable explanation about the study and consent forms before confirming their agreeing to participate, allowing them time to consider their participation and giving them an opportunity to have any queries answered. All participants were assured of anonymity and



confidentiality and of the right to withdraw at any stage of the study. Signed, informed consent was obtained from all participants prior to interview. It was emphasised to patients that the study was independent of their medical treatment and that neither participation nor withdrawal would affect their care.

### **8.4.3 Maintaining Confidentiality and Anonymity**

All identifying information associated with the study (interviewee profiles, digital recordings, field notes etc) was altered to protect the informants' confidentiality at all stages of the research (Smith, 1996). All interview material was coded, e.g. KI 4 (Key Informant participant, number 4) and participants' names and identifying features (e.g. postcode) were removed from any data to be presented. Pseudonyms were used for all participants to protect identity. Any identifying personal details were changed where they threatened to reveal identity, particularly in the rheumatology field where the percentage interviewed is a substantial fraction of the whole population. In this case recognition could be possible e.g. where a title, like Professor, plus age could identify a consultant. References to hospital locations and institutions and doctors were changed within transcripts in accordance with a fictional key for the transformation of names, places, hospitals etc. to composite identities.

### **8.4.4 Data Protection and Management**

Identifiable data relating to respondents e.g. addresses for correspondence and sound files etc. were stored on a single PC which was secured with a password access for author only. There was no file-sharing capacity and a firewall was used to prevent unauthorised network access, up-to-date anti-virus software was in operation. All back-up files on disc and paper copies of transcripts were kept in a locked file. No addresses or correct names were used to label PC files. It is planned that research files will be deleted by physically destroying discs when these are no longer required. No data containing unique identifiers was sent over the Internet.

### **8.4.5 Protection from Harm**

Provision was made for any patient/s who may have become upset or distressed by talking about their pain experiences and an independent advisor was assigned to the project. This individual agreed to be contacted by any patient who wanted support or to continue discussions. The independent advisor was an Arthritis Care co-

ordinator and lay expert in RA. Alternative phone numbers and written information about support widely available to those with arthritis was taken to all interviews. The interview delivery was designed to be open, allowing patients to avoid topics if they did not want to discuss them. The interviewer always attempted to be conscious of attending to the patient's level of comfort in addressing different topics, asking for permission to continue a line of questioning if it appeared the interviewee was becoming distressed or upset.

## **8.5 INTERVIEWS**

All interviews were conducted over a 13-month period by the researcher Stella Howden. Patient interviews were completed in full before the rheumatologists' interviews.

### **8.5.1 Pilot Interviews**

Pilot interviews were conducted with two patients and one rheumatologist. The primary aim of the pilot work was to gain an impression of how talk about pain in RA would proceed with both parties with the initial interview guides. They were also used as a test ground for technical and procedural aspects e.g. recording, and to enable critique of the researcher's interview technique. This resulted in identification of redundant interview questions and led to a first round of refinement of interview questions (these continued to change subtly in pursuance of theoretical development).

### **8.5.2 Interview Guides and Procedures**

Separate interview guides were developed for patients and rheumatologists based upon both the exploratory phase work and pilot interviews and in keeping with the primary research questions and aims. These open ended questions were used to cover key areas of relevance, thus helping give structure to the interview and maintaining a degree of consistency in coverage of key topic areas (important for the comparison of patient and doctor findings). The guides were used as rough templates and respondents were allowed to direct 'talk' as the format was non-prescriptive; allowing flexibility but within organised parameters (Mason, 1996). Tables 8.5.2a and 8.5.2b outline brief interview guides.

**Table 8.5.2a Basic Interview Guide for Patients (and bullet point prompts or probe topics)**

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Core Questions for Patients

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1. Can you tell me how it all started?
    - How were you diagnosed?
  2. Can you tell me about your experiences of pain from RA? What is it like, the pain from RA?
    - Are there different kinds of pain?
    - Is it ever absent?
    - What is a flare - to you?
  3. How, would you say, does pain affect your life? Examples?
    - At home, work, family, friends, relationships
  4. How do you deal with or cope with the pain?
    - What has been of value to you in dealing with pain?
    - What can you do yourself? What makes you do something about pain?
    - What makes you seek help?
  5. What do you feel doctors offer you, to deal with pain or its effects?
    - GP, rheumatologist, specialist nurse, occupational therapist, physiotherapist etc
  6. How do you feel about the medication used for the treatment of your arthritis and for pain?
    - Side effects, fears, effectiveness
  7. Can you tell me what it is like when you go for an out-patient clinic appointment, to see the Rheumatologist?
    - Good/bad/other - follow with, have you had any different experiences from this?
  8. What does the Rheumatologist do for you?
    - What is their role, regarding pain?
  9. What do you see as being as being the main purpose of these appointments?
    - Check up/alter drugs/treat pain
  10. How does the rheumatologist find out how you have been?
    - Questions - what? Examination - look/touch? Comparing flare and non-flare situation?
  11. Do you tell the Rheumatologist about your pain? How do you tell someone about pain?
-

**Table 8.5.2b Basic Interview Guide for Rheumatologists**

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Core Questions for Rheumatologists\*

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1. How would you characterise pain in rheumatoid arthritis?
  - What can influence the pain experience?
2. What would you say are the principal effects of RA, those affecting the lives of the patients you see?
  - biological, social, medical, self
3. What do you see as being your role in the management of the patient with RA?
  - Advisory? Compared to the GP?
4. What do you aim to achieve when managing a patient with RA?
  - What can medicine offer the patient? Views on patients self management.
5. What is the purpose of the out-patient clinic review appointments?
  - outcome assessment, treatment effects, monitoring
6. What information do you want at the consultation and why?
7. How do you actually assess the patient at clinic?
  - What aspects of the assessment do you look for to give you information about the patient's pain?
8. What would be your ideal, routine, clinical assessment for a patient with established RA?

---

\*Orientation - these questions are related to patients with established RA whom you would see regularly (i.e. at least yearly).

### **8.5.2.1 Nature of the interview and questioning**

At each interview the following procedure was followed:

- Re-check that interviewees have read the information sheet and the consent form;
- Reiterate the interests of the researcher and explain the nature of the interview (i.e. an informal interview where the main interest is in the interviewee's perspectives or views or experiences of pain in RA);
- Advised to stop the researcher if they feel uncomfortable at any point with any aspect of the interview;
- Signing consent forms;
- Start recording;
- Start with interviewee profile questions as settling questions that are relatively easy to answer (e.g. age).

The interviews took the form of a dialogue but were focused on the pain-related subjects within the interview guide and focussed on accounts of pain, pain experiences and understanding of pain etc. Throughout the

dialogue, questions arose from the patients' or rheumatologists' responses rather than from the ordering of the interview guide, thus encouraging a more 'natural flow' and at the same time allowing natural connections to be made by the interviewees, so avoiding disruption of their accounts. Questions were open in nature, clear, simple and neutral e.g. asking patients to tell their story of what pain is like. When issues related to the topics to be explored were evident, these were probed and qualified, sometimes by using the respondents' own language to reflect back and clarify or check that the researcher had understood what the interviewee had intended to convey (Kvale, 1996). To minimise the possibility of patients putting on an 'acceptable face of illness' the interviewer avoided invalidation of the interviewee's accounts and openly accepted their narrative through being interested and by encouraging the expression of feelings, thoughts etc. in an atmosphere of confidentiality (Miczo, 2003).

#### **8.5.2.2 Recording**

Interviews were always recorded with consent using a Sony IC portable, digital recorder (with 168 minutes recording time) with PC application software allowing download of files to a PC for transcription.

#### **8.5.2.3 Fieldnotes**

Directly after the interview fieldnotes were made and included comments about the nature of the interview experience (interruptions etc), points about method, ideas emerging from the interview, how the interviewer might have influenced the interview process etc. (Miles and Huberman, 1994).

### **8.6 MANAGEMENT OF INTERVIEW ACCOUNTS**

The interviews produced over 53 hours of audio material. Each interview was transcribed verbatim within 48 hours, producing over 900 pages of transcription in total. During transcription any initial thoughts, ideas, links with previous findings or new questions arising were noted (Miles and Huberman, 1994). All interviews were coded and rendered anonymous at the time of transcription. Non-verbal behaviour was noted as part of the interviews (e.g. 'patient demonstrating limitation of hand movements') but other gestures e.g. facial expression were not noted. A short pause was indicated by (...), punctuation was added without altering the sense of the original interview. Transcripts were printed for initial proof reading and 'cleaned' before uploading into Atlas.ti® (Muhr, 1997).

## 8.7 METHODS OF ANALYSIS

### 8.7.1 Theoretical Background Review

The theoretical background for the current study which informs the analytical approach and procedures used is re-stated in Table 8.7.1.

**Table 8.7.1 The Researcher's Theoretical Perspectives Pertinent to the Analytical Process**

Theoretical perspective	Researcher's Perspective for the Study of Pain Meanings
The status of the textual pain accounts	<ul style="list-style-type: none"> <li>• Pain accounts are co-created with the interviewer.</li> <li>• Pain accounts are not considered to represent facts or explicit experiences but are representative of how the individual constructs and reinterprets events.</li> <li>• Pain accounts can reveal something of 'reality' (e.g. extent of understanding) and something of the wider influences which shape respondents' conceptions of pain e.g. culture.</li> </ul>
The nature of the analytical reading – a qualitative, interpretive reading	<ul style="list-style-type: none"> <li>• Focussed upon the communicative aspects (rather than on grammatical or syntactic rules) and sections or words within accounts which inform the study aims.</li> <li>• Attend to the content of the transcripts, to what the respondent says he/she experienced, thinks etc. Exploring what accounts are about or what they convey, rather than attending to how the process of the interview influenced what was said or considering the truth or falsehood of the account.</li> </ul> <p>Two levels of analytic reading:</p> <ol style="list-style-type: none"> <li>1. Accounts are taken at face value and viewed as articulations of respondents' beliefs etc. given the questions and context. Analysis of the accounts for experiences and ways of understanding pain are explored to present a descriptive account of shared and personal meanings of pain in RA</li> <li>2. Accounts are viewed as a window on how contextual, social, personal, experiential and cultural dimensions may shape the account (an interpretive reading).</li> </ol>
Analytical sensitivities	<ul style="list-style-type: none"> <li>• Consideration of the inter-subjective meanings generated by the individual in society and the cultural-historical context, which shapes collective, linguistically available meanings.</li> <li>• Consider how personal and experiential factors may influence pain meanings e.g. age, experiences etc.</li> </ul>
Approach to quality control in analyses	<ul style="list-style-type: none"> <li>• Promoting analytical credibility through rigorous study design using various, relevant strategies and methods.</li> <li>• Account for the researcher's influence in analysis.</li> </ul>
Representation of findings and themes	<ul style="list-style-type: none"> <li>• Interpretive themes are based upon findings grounded in respondents' accounts and supported by appropriate quotations with clear distinction between the accounts, the application of the analytical framework and the researcher's interpretation in the presentation and relevance of this.</li> <li>• Presentation of abstracted themes and inter-relations which describe, re-present and account for the pain phenomenon in RA, which provide explanation for particular dimensions but do not address causality nor describe a complete 'theory' of pain in RA.</li> </ul>

## 8.7.2 Definitions of Analytic Terminology

Qualitative analysis is noted for the use of confusing terminology where words such as coding and indexing can have a variety of meanings. Analysis is used as a collective term for all handling, sorting and processing of accounts whilst moving towards the presentation of findings (Bryman and Burgess, 1994). To aid clarity and avoid confusion, the terms used in analysis are defined in Figure 8.7.2. Figure 8.7.2.1 illustrates the interactive nature of the research process.

**Figure 8.7.2 Definitions of the Terminology Used in Analysis**

### Accounts

Refer to what is generated through interview i.e. textual transcripts.

### Categories

A term used to describe a group of coding words/labels that are related. For example, the labels 'Fear of Side Effects' and 'Concern about Tolerance' would be categorised under 'Drugs - Pain'.

Two types of categorisation were used in the study supporting account indexing:

1. Descriptive categories are simple descriptors of the nature of the codes grouped e.g. 'Consequences of pain – financial'.
2. Conceptual categories are interpretive products where the phenomenon are re-framed e.g. 'private and public accounts of pain'.

### Coding

The process of labelling a section of transcript with the authors chosen key words, this is done line-by-line and sections may be words, lines, paragraphs or whole cases.

### Cross-sectional analysis

Comparing and contrasting features and qualities of categories and themes across the whole set of accounts.

### Findings

Used in preference to the term 'data' and refers collectively to all information generated or gathered e.g. transcripts, fieldnotes etc.

### Indexing

Systematically applying a set of indexing categories and codes to the text.

### Non cross-sectional analysis

Through reading and analysing accounts from an individual specifically for what these might add to the understanding of a phenomenon.

### Research diary

Used to record the thoughts and processes undertaken when working with accounts. Used to chart changes in thinking, why and when they occurred, to keep track of analysis and what informed movement from a descriptive text towards the abstract.

**Figure 8.7.2 (continued) Definitions of the Terminology Used in Analysis**

Theme/s

Describes a pattern found in the accounts but its use varies from describing the findings to interpreting a dimension of the phenomenon (Boyatzis, 1998).

Three types of theme are used in the study:

1. Sub-themes or supporting themes: these are close to the actual text of the accounts, identified directly from the accounts or respondents' words (e.g. 'expect pain in RA' is a descriptive sub-theme).
2. Key themes: these are conceptualisations of underlying patterns in the pain accounts and are identified as underlying or being a substantive element of the phenomenon of pain in RA. These are typically formulated from several, inter-related sub-themes e.g. 'pain as a symptom' is a more abstracted concept than the related sub-theme e.g. 'RA damaging the body'.
3. Core themes represent the central issues that are proposed to underpin key themes i.e. concepts fundamental to respondents' pain meanings. These are evolved from key themes and are inter-related to the themes as well as linking them, the main properties of key themes are subsidiary to the core themes which explain them e.g. 'legitimacy of pain' is a core theme related to multiple key themes.

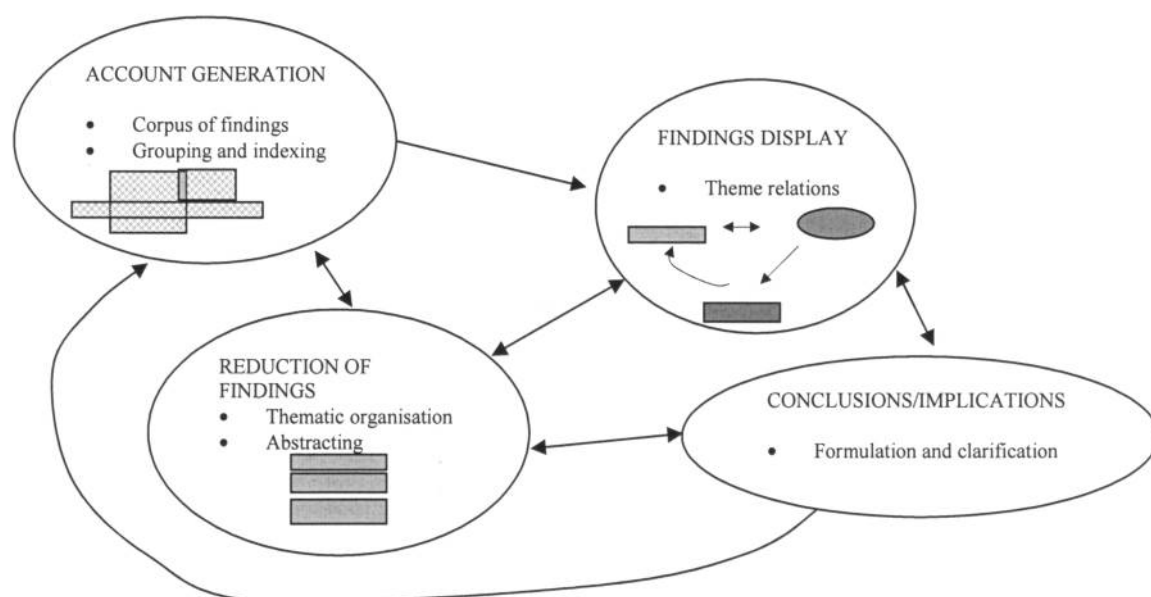
Theoretical memos

These are descriptions of the evolving understandings and developing theories arising and relate to the researcher's thoughts at they arise in the process of coding and indexing and from the apparent inter-connection of themes. These are used to record the links between themes and evolving interpretive steps and phases. These links are the basis of higher levels of abstraction.

Unit of analysis

A unit of analysis is defined as a segment of text e.g. a group of words, sentences or parts of text that relate to, or reflect, a statement about pain. These text segments are then assigned a label or code that reflects its qualities or content.

**Figure 8.7.2.1 Analysis: an interactive, iterative process model (Adapted from Miles and Huberman, 1994, p12; Holliday, 2002, p100)**





### 8.7.3 Initial Coding Categories and Indexing the Accounts

The way in which findings are initially organised, sorted and indexed impacts upon the what can be done at later stages and what kind of explanations can be developed (Mason, 1996). In order to gain a sense of the nature of pain accounts the transcripts were read repeatedly as they became available. The accounts were then fragmented. To optimise the interpretive options and maximise capture of multiple pain meanings, the accounts were indexed using two types of pre-defined category lists, descriptive and conceptual, plus an open-coding technique. The open-coding technique involved labelling relevant units of analysis with a word or phrase that was grounded in the essence of the respondent's account e.g. 'pain sensation as frightening'. These labelled units of analysis accumulated as each interview was analysed. Text that had been labelled similarly was then grouped into grounded categories to look for patterns or similarities between texts or alternatively to seek out contrasts with the characteristics of other categories previously outlined (i.e. the descriptive and conceptual categories).

The literature and topics arising from the key-informant discussions informed descriptive categories. Examples of descriptive category items were: Pain - cause, Pain - self-management, Pain - treatment/medical etc. Units of analysis, which appeared to fit two or more codes or categories were, initially, double-coded to allow later refinement when further comparative text sections became available. This then facilitated the adoption of a variety of perspectives arising from study of the coded findings and from those stages of the analysis, where the subtleties of sub-themes/key themes were developing. Similar descriptive categories were applied to patient and rheumatologist accounts (See Appendix 10.1). This was instrumental in allowing the comparative study of pain concepts at the final stage of analysis since other grounded themes were obviously different from each group as only patients had experienced the pain of RA. [None of the rheumatologists reported having RA themselves when asked at interview.]

Conceptual categories were informed by the literature. These related to processes or influences which may underlie a phenomenon or which form part of its construction. Examples of this would be:

- Responsibility for pain; and
- Private and/or public accounts of pain.

Conceptual categories were used sparingly lest the analytical process became constrained or focussed on existing processes thus risking the recognition of new characteristics in the accounts. Another possibility arising might

have been a move to premature closure of the analysis through the influence of findings made by others. Here it should be said, however, that the availability of categorisations made by others was helpful in that it allowed comparisons to be made (see Appendix 10.1 for initial categories).

As coding advanced and more accounts were indexed and more categories were filled, these were cross-referenced with open-codes. The focus was then on developing emergent sub-themes and key themes, reducing and refining these. As this progressed, conceptual categories became more abstract and broader, subsuming a number of initial categories. For example, the 'grounded' themes:

- body incapacitated by pain;
- fear in the face of pain; and
- pain directing all attention to body;

became components of the key theme related to conceiving pain as: 'Pain Overwhelms and Engulfs'.

#### **8.7.4 Use of the Constant Comparative Method**

In order to transform the grouped sections of texts into more meaningful and refined sub-themes and themes which would convey notions of the essence of pain and supporting processes, three stages from the constant comparison method were used cumulatively (Glaser and Strauss, 1967; Strauss and Corbin, 1998):

1. By initially coding units of analysis in multiple ways to generate full coverage of the varied incidents in text related to pain talk. These new coded texts in various categories were then compared to others similarly coded, comparing across the sample accounts to explore the properties related to a recognisable theme.

2. By continually refining the properties of a theme by finding similar positive or negative instances of a related issue e.g. views on the side effects of a drug from those with and without medical training. Themes were further refined and reduced in number by identifying the higher order concepts which bound them, this being supported by a focus on account generation (i.e. through modification of questioning designed to probe specific areas) and through the use of theoretical sampling. Theoretical sampling further developed the understanding of themes by highlighting participants who did not 'fit' the developing theory (deviant or negative cases) or participants who could provide an explanation for an observed characteristic. For example, when the researcher

would seek sampling of those with a medical background to further explore patient concerns about medication - were they any different from views of other participants, and, if so, different in what way or ways?

3. Analytical and sampling work was continued to the point of theoretical saturation i.e. where no new properties within each theme arose and there was no advancement in interactions and when that point was reached where no extra information was gained or themes were not refined further.

### **8.7.5 Methods Supporting the Development of Themes and Inter-Connections**

Theoretical memos were produced throughout the analytical processes to keep track of both analysis and that which informed movement from a descriptive piece of text to a more abstract level, this included thoughts about theoretical sampling (Strauss and Corbin, 1998).

A research diary was kept to keep track of the following:

- Changes in thinking and why they occurred;
- Changes in thinking about the analytical process;
- Additions to or removals from the coding lists;
- The collapse or refinement of a code;
- How any of the above affected a developing theme.

Another source of information was through fieldwork notes written immediately after interview completion.

These notes described instances such as:

- Interpretive moments where observation gave rise to an idea or hypothesis;
- Noting influence on interaction caused by the presence of another person at the interview;
- Failure of a question to elicit narrative.

These notes were reviewed at the appropriate time during analysis since they remained connected to the context, time and the individual interviewed (Warren, 1986 in Dowell et al, 1995).

To support the generation of adequately developed key themes, qualifiers were outlined for each theme and all key themes were tabulated in this format (for an example see Appendix 11.1; Boyatzis, 1998):

- Theme label;
- Definition and description of the nature of the theme;
- Reporting of the supporting/sub-themes and explanation of exclusions, reporting of cases that appeared not to 'fit' (e.g. negative cases).

Grouping the findings according to respondent's contours within their respective groups was used to assist in understanding pain accounts. For example, comparison of rheumatologists' pain management accounts set against a background of work in affluent or non-affluent areas. This was possible through having previously documented respondent characteristics e.g. age, work place, number of years working in rheumatology etc. and having loaded this information into Altas.ti ® with the respective accounts. Diagrams, conceptual maps and tabulation of findings were some of the diverse means used to link themes or develop ideas about what processes or influences related to themes (Miles and Huberman, 1994).

### **8.7.6 Non-Cross Sectional Reading of Accounts**

As well as analysing accounts for similarities and differences across sample groups and between patients and doctors, non-cross sectional account analysis was also carried out. A longitudinal analysis of the account was made, including attending to the way the respondent told the story, its ordering, any contradictions and definitive or discrete features of a particular case. This was particularly relevant in accounts relating to patients' pain experiences since life events, biography and context are known to have a bearing upon the meaning of pain for the individual (Bury, 1982 and 1988). The nature of patients' narrative conveyed personal and specific detail related to pain. When the account was considered as a 'whole' or an individual case this added greater understanding of the phenomenon e.g. the patient who reports experiencing persistent pain at an early age reveals something of the importance of age and expectations of pain. Non-cross sectional reading was important in cases where themes emerged for one individual but not for others, in these cases, explanation for the majority could sometimes be found in examining the particulars of the negative or deviant case (Mason, 1996).

### **8.7.7 The Use of Simple Counting**

Simple counting of well defined and recognisable illustrations within the transcripts was used where this might enhance the credibility of the findings presented or show the extent of the phenomena (Seale, 1999) e.g. 16 out of 16 rheumatologists reported that medications could be used to moderate patients' pain in RA.

### **8.7.8 Software Supporting Processing of the Findings**

The data software package Atlas.ti<sup>®</sup>. 4.2 (Muhr, 1997) was used to support the analysis processes, predominately through use of coding and retrieve functions. Units of analysis were coded and could be recalled allowing comparison of sections of text across the set of findings as well as building links through the text of any one case. The software facilitated the storage and retrieval and modification of stored lists of codes, memos about possible connections, building ideas and connections between codes which were evolving. It was also useful for referencing back to the original text, to re-check (in the context of the whole account) any emerging relationships, which required verification. Use of the 'hypertext' links, which connect sections of accounts and allow recall of sections in the order in which they appeared was used to retain contextual or narrative structure where this was deemed relevant to interpretations.

## **8.8 STRATEGIES USED TO PROMOTE RIGOUR WITHIN ANALYSIS**

### **8.8.1 Peer and Expert Review of Accounts, Interpretations and Evolving Concepts**

At varied stages of the analytical process accounts, interpretations and evolving conceptual work was reviewed and scrutinised by three others at team debriefing meetings. The backgrounds of the team varied, providing diversity of interpretive perspectives applied by each to the findings (i.e. sociology, qualitative research, physiotherapy, occupational therapy and chronic pain research). Initially, accounts and emerging analytical workings were discussed with the team to clarify both the foundations of interpretive development and the plausibility of interpretations and also to assist in that ensuring interpretations did not only appear justifiable to the researcher.

At several stages of analysis double transcript coding was undertaken (with the researcher and supervisor reviewing four cases in their entirety each time). This reliability exercise was used only to confirm agreement of recognition of key themes and similar groupings rather than quantification of the level of agreement. Where there was disagreement these were discussed and the descriptor refined or re-defined until the point of agreement. Nearing the end stages of analysis findings were presented to several 'expert-patients' (key informants, KI 1 and KI 2 who both had RA, see Section 8.2.4) and a rheumatology nurse practitioner who had extensive experience of working with rheumatologists and patients. [The nurse was skilled in giving counsel to patients and was often privy to their concerns about illness as well as their experiences of consultations with the rheumatologist.] It was anticipated that the key informants and the nurse practitioner would confirm recognition of the nature of the descriptive themes. They were asked for their impression of the themes generated and for any competing explanations arising. Similarly, the findings were presented to three different hospital based, multidisciplinary rheumatology teams (these included rheumatologists, specialist rheumatology nurses, physiotherapists, occupational therapists and podiatrists) for their impressions of the work and the usefulness and relevance of the findings. They were also asked for competing explanations or alternative interpretations. All responses from meetings, such as the validation or invalidation of points, were noted and these were integrated with the memos used in the final synthesis of the findings.

### **8.8.2 Respondent Validation**

Member checking or respondent validation refers to presenting the researchers' analyses back to the participants from whom the account was generated and asking them to evaluate its adequacy, for example, the adequacy of interpretations and whether the findings appear to match the respondent's view (Bryman, 2001). Four patients were selected for member checking, each having different characteristics and varied pain accounts. Each was presented with a summary account from preliminary analysis of their interview i.e. summary of their main thoughts, feelings, experiences of pain and RA. The aim was to identify whether patients recognised this as a complete account or whether any areas/topics had not been explored which the patients, on reflection, felt were important or had been missed. They were also asked whether they would confirm or reject initial interpretations (Lincoln and Guba, 1985). These summaries were mailed to patients (with their permission) and a follow-up phone interview used to gather feedback; notes were taken during the phone call. The findings from the respondent validation informed subsequent interviews (see Appendix 13.1 for details).

### 8.8.3 Representational Style of the Findings

Findings and discussion are presented together to facilitate clarity when comparing of synthesis of current findings with existing literature (Strauss and Corbin, 1990). Distinction between the point where 'raw' accounts end, and synthesis and interpretations begin, is maintained by presenting quotations along with synthesis of accounts before interpretive comment and discussions. The grounded textual accounts (quotations) are presented to allow judgement by the reader of the validity of the interpretation (Strauss and Corbin, 1990). Quotations are used where they exemplify the emergent theme being presented within the findings, where they typify the views of the sample or where they are unique or particular. Integration of simple counts or quantitative summarisation of the findings is included where appropriate. Each quote is labelled with the interviewee code e.g. P1 or R1 (patient 1, rheumatologist 1 respectively) along with a pseudonym allowing the reader to easily judge the spread of use of quotes among respondents.

Where cases failed to match higher level themes, scrutiny may enhance the security of conclusions drawn (Patton, 1990). Thoroughness of examination and presentation of negative cases is attempted along with highlighting those cases where there is evidence contradicting explanations proposed. This may either, provide further support for the argument or, show the researcher had been open to all the findings and had attempted an explanation. In an attempt to account for the researcher's influence and its impact on the analytical processes (and ultimately on the nature of the findings) a reflexive self-aware approach is adopted (Grbich, 1999, p65). Fieldwork notes and those from memos and the research diary are incorporated into the presentation of the findings/discussion to highlight how the researcher interpreted and shaped the findings.

## **9 CHAPTER NINE - FINDINGS AND DISCUSSION: PATIENTS' THEMES**

### **9.1 INTRODUCTION TO THE FINDINGS AND DISCUSSION CHAPTERS**

For ease of interpretation and to enable the reader to judge the credibility of links made between respondents' actual words, interpretation of these accounts and the validity of the consequent evolving arguments, findings and discussion are presented together. Nine patient-themes and six rheumatologist-themes were developed and these are presented in Chapters 9 and 10 respectively. Each theme represents a pattern found within the interview accounts and is described before explaining the core concepts that inter-relate with and/or underpin perceptions of the pain phenomenon in RA. Chapter 11 is dedicated to comparing and contrasting key themes from the patient and rheumatologist groups and focuses upon the implications for clinical pain management. In Chapters 9, 10 and 11 a consistent framework is used to group the main themes, ordering these around three types of pain meaning:

- Shared meanings i.e. patients' and rheumatologists' conceptions of the significance or connotations of pain in RA;
- Consequences of pain; and
- Clinical-contextual meanings of pain i.e. pain meanings related to clinical pain management and talk about pain at consultations.

To contain the verbosity of these chapters, supporting quotations are used only where necessary to substantiate an explanation or where they clarify a more complex argument. Each quote is labelled with the respondents code number (e.g. P1 - patient 1 or D1 - rheumatologist 1) and their alias. The letter 'I' is used to denote the interviewer's speech.

### **9.2 AN OVERVIEW OF PATIENTS' THEMES**

The key themes presented in this chapter are listed in Tables 9.2a, 9.2b and 9.2c. In these tables, each key theme has an assigned number and descriptive theme label. Several sub-themes (which support the key themes) are also presented, these have been selected as they are considered to be the principal sub-themes that support key themes



(for the full listing of the sub-themes see Appendix 11.1). Within each table ‘core themes’ are listed (in the final column) these represent the central issues that are proposed to underpin the key themes. These core themes are inter-related to and link key themes and are discussed at the end of the chapter.

**Table 9.2a Patients’ Shared Meanings of Pain – listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
1.	Pain as an expected symptom of the disease acting upon the body	<ul style="list-style-type: none"> <li>• Pain as an unpleasant sensation from the body</li> <li>• Pain as fluctuating and uncertain</li> <li>• RA damaging the body</li> <li>• Pain signals body dysfunction</li> <li>• Pain as a diagnostic indicator for RA</li> <li>• Expect pain in RA [no total control]</li> <li>• Pain progressing/worsening with time/age</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attribution of pain to RA – the disease</li> <li>• Perceived threat to self from pain</li> <li>• Perceived legitimacy of pain</li> <li>• Perceived responsibility for dealing with pain</li> </ul>
2.	Pain as a useful signal of body/mind stress or imbalance	<ul style="list-style-type: none"> <li>• Pain modified by mind/action [self control of pain]</li> <li>• Differentiating pains [disease versus non-disease related pain]</li> <li>• Pain cues modification of action [self or others]</li> <li>• Accommodation/modification- practical strategies to modify pain</li> </ul>	
3.	Pain as a conflict between ‘real’ body pain and private, subjective pain	<ul style="list-style-type: none"> <li>• Pain as an ambiguous disease signal</li> <li>• Pain as subjective/personal</li> <li>• Pain as invisible to others</li> <li>• Judging legitimacy of others’ presentation or report of pain</li> <li>• Valuing clinical signs/tests to ‘determine’ pain</li> </ul>	

**Table 9.2b Patients' Perspectives on the Consequences of Pain - listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
4.	Pain as a variable disruption of life	<ul style="list-style-type: none"> <li>• Pain interfering with valued body functions, activities and performance</li> <li>• Pain altering mood/emotions</li> <li>• Pain disrupting social/family roles</li> <li>• Pain interfering with relationships</li> <li>• Making positive comparisons (comparing self with others regarding pain)</li> <li>• Adopting pain within life</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attribution of pain to RA – the disease</li> <li>• Perceived threat to self from pain</li> <li>• Perceived legitimacy of pain</li> <li>• Perceived responsibility for dealing with pain</li> </ul>
5.	Pain overwhelms and engulfs - threatening self and body	<ul style="list-style-type: none"> <li>• Intensely unpleasant, severe and widespread pain</li> <li>• Fear in the face of pain</li> </ul> <p>Suffering with pain:</p> <ul style="list-style-type: none"> <li>• threat to integrity of mind</li> <li>• threat to integrity of body</li> <li>• threat to integrity of self</li> <li>• Seeking medical help</li> </ul>	
6.	Pain as prolonged suffering	<ul style="list-style-type: none"> <li>• Persistent, prolonged, severe pain within the body [minimal fluctuation]</li> <li>• Permanent loss of basic valued activities</li> <li>• Hopelessness in face of pain</li> <li>• Lack of ability to alter/control own pain</li> <li>• Treatment options- using last medical resorts</li> </ul>	

**Table 9.2c Patients' Perspectives on Clinical-Contextual Meanings of Pain - listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
7.	Negotiating pain to match perceived responsibility	<ul style="list-style-type: none"> <li>• Medical expert assessing the body for disease signs [linked with Theme 1]</li> <li>• Differentiating roles for the rheumatologist, nurse practitioner and GP</li> <li>• Concealing psycho-socio-emotional issues from the medical expert</li> <li>• Dealing with psycho-social-emotional issues independently</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attribution of pain to RA – the disease</li> <li>• Perceived threat to self from pain</li> <li>• Perceived legitimacy of pain</li> <li>• Perceived responsibility for dealing with pain</li> </ul>
8.	Unacceptability of complaining about pain - maintaining positive relations	<ul style="list-style-type: none"> <li>• Moaning/complaining about pain repels others</li> <li>• Awareness of long term relations with doctor (potential threat to long term relations through complaining)</li> <li>• Be credible when presenting pain to doctor - presenting 'legitimate' complaints only</li> </ul>	
9.	Evaluating pain in anticipation of analgesic interventions	<ul style="list-style-type: none"> <li>• Expectation of treatment stasis with non-complaint</li> <li>• Negative views of analgesia [progression, addiction, tolerance, side effects, interactions]</li> <li>• Secondary importance of pain treatment in comparison to disease treatment</li> </ul>	

### 9.3 PATIENT SAMPLE CHARACTERISTICS

Twenty-nine adults with self-reported RA and current daily pain were recruited to the study. Sampling was purposive, specifically sampling for a diversity of pain experiences and pain accounts. Sixteen females and thirteen males volunteered, mean age 55.8 years (SD 13.7), with representatives for each decade of life from 30s to 80s. The majority of patients were retired (62%) with 50% of those having been medically retired. Eight patients were employed in a variety of occupations and three were unemployed. Educational backgrounds varied from 9 to 18 years of schooling with a reflective mix of social classes. Each social class was represented with exception of class V (unskilled manual, classified in accordance with the Register General's classification of social classes, Reid, 1989). Carstairs's deprivation scores were identified, based upon patients' postal code. These

are recognised predictors of health status in Scotland (Carstairs and Morris, 1991, see Appendix 9.2). Deprivation scores can range from 1 to 7 (7 being the most deprived category). Within the sample there were representatives from each deprivation category (Mean: 3.90, SD 1.14, Mode 4). See Figure 9.3 for a summary of the patient sample characteristics.

**Figure 9.3 Descriptive Statistics of the Patient Sample Characteristics (n=29)**

Number of females	16
Number of males	13
Mean age (years)	55.8
SD	13.7
Range	34-87
Numbers within age categories	
30-40	5
40-50	7
50-60	5
60-70	7
70-80	4
80-	1
Mean duration of RA (years)	11.3
SD	9.4
Range	1-37
Occupation (present or past)	
Non-manual (I, II, IIIN)	19
Manual (IIIM, IV, V)	10
Mean deprivation score	3.9
SD	1.14
Range	1-7
Living with partner	13
Living with partner + children	12
Living alone	4

Sixty-six percent were in or had been in non-manual occupations and 34 % in manual work. Twenty-three patients were married, four divorced or separated and two had been widowed. All patients were Caucasian.

The number of years since diagnosis varied from 1 to 37 years, mean: 11.3 years (SD 9.4). Patients self-rated their Global Functional Status (see Appendix 9.1; Hochberg et al, 1992) between classes II and III/IV. The majority selected either II (i.e. able to perform usual self-care and vocational activities but limited in avocational

activities, 28%) or III, who perceived they were limited in both vocational and avocational activities but could self-care (51%). All patients regularly attended rheumatology out-patient clinics for reviews with their consultant rheumatologist, attending on average three times per year. Most patients had attended their current rheumatologist for over five years. Nine patients had had surgery related to their condition (31%) and all reported using multiple medication regularly. On average, patients reported using four to five different classes of medication (e.g. analgesics, NSAIDs and DMARDs).

Two patients were active members of Arthritis Care and one was involved with the National Rheumatoid Arthritis Society (NRAS). Seventeen percent of patients reported receiving some kind of formalised education/training about RA, and living with RA and 41% had known of someone (family or friend) who had RA before they were diagnosed. Seven patients had some medical background or knowledge. Table 9.4 presents an overview of the sample with patients' codes and pseudonyms (all gender specific names).

## **9.4 PATIENT RECRUITMENT**

Eleven patients were recruited from the 'Steeltown' region where a community based rheumatology service operates i.e. hospital based rheumatologists work with a multi-disciplinary team who are deployed to patients' homes when necessary. The remainder lived within the Broomtown region, served by hospital based rheumatology services at three sites. Seventy-five percent of patients were recruited through posters and leaflets displayed in hospital rheumatology out-patient waiting areas. Two had taken recruitment leaflets upon discharge from a rheumatology ward, others who were already involved told two more about the study and three were recruited via leaflets distributed at local Arthritis Care meetings.

Theoretical sampling was employed to specifically explore and develop the theme of pain legitimacy. Two additional patients (P24 and P26), who had experience of having sero-negative status (see Appendix 1.1) were recruited through rheumatology out-patients clinics. Two patients, who had experience of specific training to educate others about arthritis, were recruited to further examine differences in knowledge/understanding of pain. (P27 - arthritis care instructor, P28 - Patient Partner, See Appendix 1.1).

**Table 9.4 Summary of Patient Sample Characteristics**

Code/name	Age (yr.)	Years since diagnosis	Functional status (ACR rating)	Work status	Occupation (past/present)	Clinic visits (yearly)
P1 Andrew	66	26	III/IV	Retired	Doctor	6
P2 Barry	58	15	III	Medically retired	Bus driver	2
P3 Carrie	76	32	III	Retired	Cashier	2
P4 David	76	15	II	Early retirement	Minister	2
P5 Eddie	57	1	II	Works (full time)	Painter	4
P6 Fran	49	10	II	Works (full time)	Nursery nurse	4
P7 Gwen	87	37	III/IV	Retired	Receptionist	2
P8 Harry	63	20	III	Medically retired	Bus driver	2
P9 Ian	63	4	III	Early retirement	Electrician	2
P10 James	70	19	III	Medically retired	Joiner	2
P11 Keith	66	1	II	Retired	Architect	4
P12 Lyle	47	11	III	Medically retired	Supervisor	6
P13 Moira	35	1	III	Works (part time)	Childminder	3
P14 Nan	70	3	III	Early retirement	Cashier	3
P15 Peter	57	3	III	Medically retired	Truck driver	2
P16 Rose	47	13	III	Medically retired	Nurse	2
P17 Sarah	45	5	II	Works (part time)	Manager	4
P18 Tess	65	15	III	Retired	Shop assistant	3
P19 Victor	54	20	II/III	Medically retired	Warehouseman	4
P20 Wilma	49	6	III	Medically retired	Assistant cook	2
P21 Yvonne	38	7	II/III	Unemployed	Hairdresser	3
P22 Ann	53	2	II/III	Works (full time)	Health visitor	2
P23 Bill	66	1	III	Medically retired	Policeman	4
P24 Catriona	38	8	II/III	Unemployed	Mortgage advisor	4
P25 Darren	62	5	III	Retired	Nurse/salesman	2
P26 Ella	43	14	II	Works (full time)	Manager	2
P27 Polly	46	16	III	Unemployed	Bank clerk	4
P28 Juliet	37	14	II	Works (full time)	Lab worker	2
P29 Clare	34	5	II	Works (part time)	Therapist	3

## 9.5 PATIENT INTERVIEWS

One interview was conducted at Queen Margaret University College, Edinburgh, at the patient's request, all others were conducted at the home of the patient. All participants consented to having the interview recorded. Interviews lasted on average 86 minutes (range: 40-123 minutes, total recording time: 41 ½ hrs.). In six interviews a partner contributed to the interview and in each case partner participation was brief. After a review of the purpose of the interview and having obtained written consent, settling questions were presented. In several cases these questions initiated a pain narrative relevant to the study aims. As questioning was intended to be flexible and in order to promote the generation of natural links and explanations in the patient's own words, the interviewer allowed the patient's story to unfold 'naturally' where this was relevant to the broad topic area.

Patients said that they had enjoyed the interview experience and were keen to talk further. Most visits lasted 2-3 hours. Patients reported the interview had given them a rare opportunity to talk freely about their daily experiences and feelings, something they did not normally engage in with friends, family or health professionals. This suggested that a supportive element of interviewing in chronic illness can promote interviewees to feel valued, as if they are making a contribution through informing.

## **9.6 PATIENTS' SHARED MEANINGS OF PAIN IN RA**

Shared meanings relate to 'ways of knowing' that are shared within any particular culture e.g. pain being associated with arthritis (Bury, 1988; Kleinman, 1988). Three patient themes were classified under this heading thus reflecting their common foundation in western, biomedical conceptions of pain:

Theme 1 - Pain as an expected symptom of the disease acting upon the body;

Theme 2 - Pain as a useful signal of the body/mind stress or imbalance;

Theme 3 - Pain as a conflict between 'real' body pain and private, subjective pain.

### **9.6.1 Theme 1: Pain as an Expected Symptom of the Disease Acting upon the Body**

This dominant account of pain in RA was defined by patients' conception of pain as a negative, sensory experience that originated from body tissues and was indicative of dysfunction or disease within those body tissues. Patients perceived pain to have a real, organic cause i.e. it was related to RA, the disease. In association with this relationship to disease, pain was also seen to be an expected, on-going, unpleasant experience for those diagnosed with RA i.e. they expected that, as rheumatoid disease progressed with time, and was compounded with the effects of ageing, pain, from the body, was likely to worsen.

#### **9.6.1.1 *Pain sensations and disease processes***

The accounts of all twenty-nine patients included talk about pain as a symptom of the disease (RA). Talk focused upon describing the sensory qualities of pain (e.g. aching), the intensity of pain, the spatial extent of pain

(primarily linked to being within or around joints); how pain sensation changed with motion and the duration of pain in all of these scenarios.

**I:** How does the pain from the arthritis feel to you? **Keith:** Well it was like when you had an injury to your knee when you were younger, it was damn sore and then it went away. With this, the pain didn't go away, it was there all the time. I do get pangs and twinges of pain, shooting pains in my thumb and shoulders occasionally. .. if I walk down stairs I do get a pain but it is not constant like it was.. [P11 Keith]

Pain accounts were characterised by biomedically orientated explanations regarding cause, most commonly relating pain to physiological disease processes (i.e. inflammation) or the sequelae of active disease e.g. structural joint damage. David (P4), who had no medical background, presented an account of the different types of pain and associated causes he perceived as related to his condition; each pain 'type' being related to different disease factors (e.g. swelling from inflammation, mechanical pain from movement of damaged tendons). His quotation exemplifies other accounts where pain was associated with patho-physiological processes or structural damage. In his account, David integrated his pain experiences with signs of disease (e.g. observing a swollen joint) and feelings of pain upon movement, along with medical explanations he had received in the past (when he ruptured a tendon in his hand). Together this forms an explanation of the nature and causes of pain in RA:

I think there are different kinds of pain [in RA]. The pain of the swelling when it was at that stage, where it got me was, I couldn't take hold of anything, well I probably could take hold of it but the pain would be too great when I did .. But it wasn't as much that they were sore, if you sat at rest you didn't really feel it but if you were to move them about you were in deep trouble. So that is one kind of pain, but there is a second kind of pain, which I think is a whole body thing. What you are actually doing is driving against this all of the time and that actually wears you out perceptively. .. And I think there is a third one, and this is what this is [POINTS TO WRIST] which is beginning to use all the muscles again after the swelling goes down. That's actually a sharp pain and that's the one that bursts tendons I think, if you are not careful. So that would be my understanding. They could be damaged now, because I think they are probably rough in their channels that these tendons are running in. [P4 David]

The preceding example (P4 David) of a pain account was typical, the patient appearing to build upon bodily, physical experiences and increasing knowledge of RA gleaned from medical interactions from the time of diagnosis onwards. The association between pain experiences and disease processes was reinforced when pain experiences felt to 'fit' medical classification of RA e.g. pain reports assisted doctors in making the diagnosis.

Distinction was made between pain experiences that were described as intense, generally widespread and with a relatively short duration in comparison to 'day-to-day fluctuating pain' of a lesser intensity. The former was



associated with a 'flare' or an exacerbation of the disease and was commonly linked with experiences of joint swelling and general feelings of being un-well and fatigued (Theme 5 presents an expanded account of 'flares'). This understanding of the pain experience as being related to changing disease activity was reinforced through the patients observation of the changing values/measures of clinical process tests (e.g. Plasma Viscosity – PV, see Appendix 1.1) corresponding to pain experiences. Furthermore, changing medical interventions, which resulted in decreased symptoms reinforced the link between the pain experience and disease processes.

.. I was 2.3,.. my plasma viscosity [PV], I keep a ten-year diary and I can look at that and see: 'Pain very bad today', and I can look at the separate sheet from the laboratory and see the levels are high. .. But you can relate the inflammatory levels to the diminishing of the pain, so I do have RA, there is no doubt about it and that is basically it. [P25 Darren]

### **9.6.1.2 Expectations of pain in RA**

Expectations of pain were closely related to the patients' perception of what they understood about the disease. For all patients the daily experience of pain was as an expected symptom of the disease and was thought likely to present in an unpredictable, fluctuating way. This understanding of pain was related to their post-diagnosis knowledge of RA as a fundamentally painful condition affecting the joints (evident in all accounts). Like other forms of arthritis this was also associated with stiffness and difficulty with body movements. Patients were resigned to believe that pain would be a daily experience and this was related to their understanding of RA as being a progressive condition that is not fully understood. All patients were aware that RA could not be cured, the majority (86%) acknowledging that medicine had yet to fully understand the cause of RA. This aspect of 'mystery' about RA appeared to mediate, in part, assumptions that pain from RA could not be fully controlled and certainly not abolished.

**I:** Did getting the diagnosis of RA change what you thought about the pain? **Harry:** Yes, quite a bit, because I had always thought with rest, when I get sore, I would use wrist supports and it would gradually go away. But then I had the realisation that it wasn't going to go away. [P8 Harry]

well, you learn from other people and you watch what they are doing and saying you know. And you say, well that's it so lets put up with it sort of style. Because there is no other ways, they are not going to cure it. They [Drs] don't know what causes it so they can't sort it out; it's just as simple as that. I just accept that. [P10 James]

Rheumatoid arthritis was therefore characterised as a progressive condition, where the outcome could not be accurately predicted. Increasing age and an expectation of body deterioration with age was anticipated to

potentially compound pain experiences and its consequences. Eddie (P5) reflects upon his thoughts at the time of diagnosis:

I knew I was going to be on the floor! I am a realist, I've been brought up on farms for quite a long time and so I know these kind of things happen and you look at all those old women's' fingers and they are gnarled and you know they weren't like that when they were young. And so it's a gradual thing, it progresses...[P5 Eddie, aged 57]

.. you know I am not as good as I was, but I am sixty-six years of age and I'm not a spring chicken any more and I'm coming to an age where older people do become affected by things and I can live with that. I can live with the fact that occasionally my fingers get stiff and sore. .. eventually through time the joints will begin to deteriorate and that's called 'old age', there is no doubt about it. [P11 Keith, aged 66]

### **9.6.1.3 Taking action associated with pain experiences**

As this theme locates pain as a symptom of disease it might be anticipated therefore that pain exacerbation would equate with action to seek medical help, for disease slowing interventions; however, behaviours associated with changing pain were complex and at times contradictory. In its simplest form, patients would appear to engage in a 'waiting game'; hoping for self-resolution but aware that pain may be an indicator of disease progression, unsure of what action to take. This would appear to be founded upon the uncertainty/variability of pain in RA and belief in the inevitability of pain in RA. However, contradiction was apparent in several accounts, Peter explained in an early part of his interview how important medical consultations were:

You know I am thinking .. if I don't go [to see the doctor] maybe it's going to get worse. So as I say, years ago you would hardly have got me to go to the doctor but now, if I think its going to help me I will be there. There are times when I sit and think to myself if there were times in the past when I could have gone earlier and not been so stupid, would I have been as bad as I am now? [P15 Peter]

Later in the account Peter explained that his pain had to be - "really sore for me to go along and see the doctor". Patients gave accounts of delaying or not seeking medical attention upon experiencing increased pain; their decisions being dependent upon multiple factors e.g. the nature of the experience (duration, quality and location), reflections upon past experiences, interpretation of what the changes might signify along with anticipation of the outcome of seeking help. Aside from the acute and incapacitating painful experiences (where medical help was more often sought quickly (Theme 5) action related to daily fluctuating or slowly worsening pain experiences was characterised by a complex mix of evaluations. The preceding accounts all emphasise that pain experiences

and their significance to patients are more sophisticated phenomena than simply a proportional symptom of disease.

#### **9.6.1.4 Theme summary**

In essence, this account of pain identifies strongly with the cultural connotations of arthritis, namely as a painful, progressive condition where associated, causal disease processes acting upon the body and the resultant damage to joints, is related to the unpleasant pain sensations. Pain is an expected experience in RA with the potential to worsen with disease progression and ageing, partly related to appreciation of limited medical understanding of the disease and to lack of cure or definitive treatments for RA. How patients make sense of pain in RA in this account is predominately a compound of the product of experience, evaluations of pain based upon lay biomedical conceptions of pain and arthritis, plus information gleaned through interactions with health professionals. Decisions to seek medical help for changing pain are complex and appear ambiguous in the accounts for non-acute phases of the illness. Factors influencing action to seek medical help included the expectation of fluctuating daily pain in RA and anticipation of worsening of pain with time and ageing.

In addition to all the preceding factors, the patient also considered how 'non-disease' factors might contribute to their pain experience e.g. activity levels; these are presented in the following section.

#### **9.6.2 Theme 2: Pain as a Useful Signal of Body/Mind Stress or Imbalance**

Again in this account of pain in RA, pain is primarily reported as being a negative sensory experience associated with body dysfunction; however, pain attributions are not primarily disease related. Pain is viewed as being potentially generated by the behaviours of the individual e.g. exercise, and can be exacerbated by situational physical or mental stresses e.g. anxiety related to work. The pain experience is related to an imbalance or over-burdening of mind or body, the latter already compromised by disease, and is a signal to the individual that they must take action to minimise or avoid these stresses or risk the pain continuing/worsening. In this way, the signals of pain can be conceived as helpful in prompting a balancing of activity or modification of a task or situation to avoid or reduce pain. Therefore pain in this instance necessitates self-management or finding ways to deal with pain independently.

Factors associated with placing a detrimental strain upon the body included undertaking physical activities that were subsequently considered strenuous or prolonged. Psychological and/or emotional burdens which could exacerbate pain included anxiety, worry, frustration or annoyance. Psychological/emotional factors were less frequently mentioned than physical factors. Table 9.6.2 lists the most common physical and psychological stressors implicated with changing pain experiences.

**Table 9.6.2 Patients' Accounts of the Physical and Psychological Factors that Modified Pain Experiences**

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Physical Stresses Modifying the Pain Experience

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Injury e.g. knocks and bumps inflicted upon the body, especially at joint regions  
 Undertaking strenuous activity e.g. heavy lifting  
 Prolonged or sustained activity e.g. prolonged walking  
 Prolonged static postures e.g. prolonged sitting  
 Body movements that are known to be painful e.g. reaching overhead

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Psychological Stresses Modifying the Pain Experience

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Anxiety, worry  
 Frustration, anger  
 Feeling low in mood or depressed  
 [Secondary effects of anxiety or frustration e.g. increased muscle tension compounding pain]

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Patients described self-appraisal of pain experiences, thinking back through previous days or hours and attempting to account for their pain experience, building knowledge of their limitations and their capacity to function with pain and in spite of pain. The pain experience was used as the patient's own diagnostic indicator, signalling a loss of balance within the body or mind, resulting in a heightened pain experience, and initiating a course of action designed to alleviate or diminish pain and accommodate for its presence. Accounts of strategies enlisted to manage such stresses were divided into two sub-themes: 1. re-defining roles, and 2. accommodating or modifying strategies. Re-defining roles refers to adapting to pain by avoiding or discontinuing specific activities previously part of the normal role/routine e.g. giving the task of shopping to a partner. Accommodating strategies refers to techniques, actions and aides that allow the individual to 'work around' pain and includes a variety of strategies, often unique to individuals and their circumstances. Figure 9.6.2 lists the practical measures used to reduce/minimise pain.

**Figure 9.6.2 Practical Measures and Strategies Used to Reduce/Minimise Pain**

- Use of aides and equipment e.g. splints.
- Pacing activities e.g. breaking up tasks with rest periods.
- Modifying movements or the way a task is performed.
- Changing medications e.g. use of analgesics before activity.
- Use of heat/cold packs.
- Use of distraction or relaxation techniques.

Examples of adaptation/strategies used, taken from two different accounts:

I have a foam mattress on my bed and a heated blanket, sometimes you want heat and sometimes you don't, it's just the way that it is. And the foam does make a big difference because before I got that the aches and pains in the morning were dreadful. I still sometimes, well the pressure on the joint is enough to cause pain and it's not necessarily a flare up. .. for a while my hands were sore and so Richard [husband] taped up all the door handles with foam because just holding a door handle was enough to cause excruciating pain in the joints in your hands. So I have to do things like that to cope with it. And these are things you sit there and think up, now how can I get round that? It's a bit like solving a puzzle. [P24 Catriona]

But it is annoying for yourself and you get uptight and the more you get uptight the more pain you get for some strange reason. **I:** have you found that? **Barry:** yes, yes, if you get uptight, your muscles tighten up, which is natural and as the muscles tighten you get more pain. **I:** how do you deal with that? **Barry:** you get up and you say to yourself, this is daft, this is stupid. What are you doing to yourself., and that is when you hit the co-proxamol. For the pain...well it does take some effect on the pain, so you take some co-proxamol. [P2 Barry]

Yvonne explains how she adapted some activities and abandoned others to assist her ability to function with pain and reduce her pain experience day-to-day:

It's definitely better than it was. I used to cry most mornings .. you adapt yourself, I mean I lay out the kids clothes every night because going up and the down the stairs in the morning if I forgot their socks, oh no.. [Sighs]... Like, I would never go to Asda at nine o'clock in the morning but I maybe go at two in the afternoon. .. We laid wooden floors in all the bedrooms, the only carpet is the one in the hall. So the only carpet I have to Hoover is in the hall.. Things like that, I don't have to Hoover upstairs... And I love gardening and I like to potter about but the whole front garden got mono-blocked. To actually move the earth, I couldn't do it.. [P21 Yvonne]

[Note - Comparison of those who had and had not received formal education and advice regarding living with RA either through Arthritis Care courses or hospital based sessions suggested there was no difference in the range and number of adaptive strategies presented.]

### **9.6.2.1 Theme summary**

This account of pain focuses upon patients' conception of pain as an experience that can be modified by non-disease factors through an over-burdening of the body or mind through physical, psychological or emotional factors. This is learned through experience and appraisal of events and circumstances, and presents pain as a useful signal to the patient acting as a cue which prompts them to modify their behaviours or strive to change physical, environmental or personal stresses. These actions are associated with reducing or limiting pain and potential harm to the body and promote less painful task completion. In this way, pain can be perceived to be useful, as an indicator of loss of balance within the body, serving as a protective mechanism initiating behavioural change and is also associated with exercising some degree of control over the pain experience.

### **9.6.3 Theme 3: Pain as a Conflict Between 'Real' Body Pain and Private, Subjective Pain**

Within these accounts of pain the patients' asserted that pain in RA had a definite organic basis or cause, but focused upon the complexity of pain as a phenomenon that was ultimately a personal, subjective experience; one that only they could know. A central issue for the patient was the ambiguity of the pain experience as something influenced by both organic and non-organic factors and the problem, which this posed, for others attempting to evaluate the legitimacy of their pain reports. Pain experiences judged to be related to demonstrable biological or patho-biological causes were afforded greater kudos or legitimacy than presentations of pain with no identifiable, organic cause, particularly in relation to clinical pain assessment. When objective indicators/signs of an organic basis for pain were deficient the patient appeared to doubt their own experience and/or fear that others (e.g. the rheumatologist) might either label them as a malingerer or associate their reported pain with an aspect of their psyche. Accounts related to the legitimacy of pain were most prevalent in talk about:

- Descriptors of their own pain;
- Evaluation of the legitimacy of their own pain and the evaluation of others;
- Desire to have pain legitimised in an objective way by the medical expert (expanded in Theme 7).

Patients' accounts of pain were often coupled with examples of how pain had affected their life or examples of what the pain experience could be compared to e.g. "It's like toothache, but in your knee (P25 Darren), "worse than childbirth" (P13 Moira). In this way, patients attempted to convey something of the nature of the pain to the interviewer who could not know how it felt. This supported the belief that pain is always personal and private and can only be explained in a way which gives some point of reference to the listener. The invisibility of pain and private nature of pain in RA was a common sub-theme:

You don't look disabled facially, they [others] don't know how sore you can be inside your body [P21 Yvonne]

#### **9.6.3.1 Judging the legitimacy of their own and other's pain**

Pain was perceived to be a more complex phenomenon than simply and directly related to biological or physical factors. It was complicated by psychological and personal factors such as changing tolerance to pain or pain accentuated by anxiety (linking with Theme 2). Patients questioned their own changing pain experience and its basis:

.. with time your tolerance of pain gets better and better and better. So, as at this moment, I would have been in quite severe pain five or six years ago. But .. your body builds an amazing tolerance to pain you know? **I:** So are you saying that if you were sitting as you are now, with these feelings and went back five years ago, they would be different? **Harry:** Oh yes an entirely different feeling. I would be in such severe pain, I would be straight to the doctor, I would be looking for some immediate aid, to get something injected. But whether it is something psychological or physical in its make-up, I don't know, but you do become used to or inured to severe pain. [P6 Harry]

Making a distinction between pain originating from the body as opposed to the mind was alluded to repeatedly in accounts, most often when referring to peer group pain behaviour. Legitimate pain or pain with an organic nature was seen to cause suffering that would be evidenced in its capacity to limit function, despite attempts to self-manage or accommodate it. A pain report without measurable or observable evidence was deemed less credible and less acceptable:



I saw this young man [at clinic] and he had a walking stick and one of the doctors came out to talk to him. He had been on holiday and had had a great time and this and that; and when he sat down you could see that he could hardly sit down for the pain. You could see it in his face you know? When he was going to his pocket to get the blood results.. he could hardly get them! And I could sympathise and empathise with the guy.., so cheery and everything, and you could see how much pain he was in... the shoes he had on, they were like Timberlands, comfortable. But you get some of these wee old women with their wee fancy heeled shoes and you think, God you think you're that bad! [exclaims] [P6 Fran]

### **9.6.3.2 Wanting pain legitimised by the expert in an objective way**

Patients were aware that the additional complexity of pain as a phenomenon could only be made known to others when specifically communicated as such. This anticipated the difficulty of evaluation of legitimate and/or non-legitimate pain, raising the possibility that the doctor might be misled or the degree of 'actual' pain concealed. Reference to peers with RA exaggerating their pain or 'swinging the lead' were made in five interviews and reference to the rheumatologist having to carefully 'determine' the legitimacy of pain was prevalent in all accounts. The following quote from Harry describing going to see a new specialist exemplifies a common concern that pain may not be accepted at face value by health professionals who have only recently been involved in their care.

And they [current rheumatologist and GP] know who I am and it's a big, big help and that's my problem with the others [new specialist], they don't know if I'm a lead-swinger or how much pain I am in. .. And I wonder whether they believe me, it's running through my mind. [P8 Harry]

Having pain legitimised as originating or being causally linked to the disease and the body (and not the mind) is highly valued if gleaned from the medical expert. This was a common account in talk about the assessment of pain at the clinic. Patients valued links found between disease indicators/measures and their personal experience of pain and the resultant validation of their pain for themselves and for the rheumatologist. Clinical tests valued by patients, related to their pain experience included: blood tests, imaging (x-ray), visible signs (e.g. swelling) and functional or clinical tests (e.g. loss of movement). Having their pain story and bodily presentation scrutinised by the doctor was valued and accepted as necessary, the doctor having the right to look for verifiable evidence or signs related to pain, thus confirming the patient experience of pain:

.. and you might go in and say, 'well I am feeling better' and they[rheumatologists] have that there [blood test results] as a kind of back up. So they look at that just to see how that has been. I suppose that if they didn't get the blood tests and the x-rays you could sit there and say anything. [P6 Fran]



### **9.6.3.3 Failed legitimisation of pain: the sero-negative experience**

Examination of three specific cases where sero-negative serology tests (see Appendix 1.1) denied legitimisation of pain was used to extend understanding of this theme. After interview with Yvonne (P21) who initially presented without Rheumatoid Factor (RF) in blood tests, two further sero-negative individuals were purposively recruited to the study (P24 and P26) to further explore the issue of legitimacy of pain. In all three accounts the lack of a positive RF test for RA was strongly identified as causing problems in gaining a diagnosis and was related to their rheumatologists doubting the reality of their pain experience. Failed validation of the legitimacy of their pain report (i.e. where there was failure to link pain with an organic/biological processes) lead to concern about how their pain and consequently 'self' was judged. With such discordance between clinical tests and patients' pain experience, patients reported feelings of losing faith in medicine and of being stigmatised with psychological labels. Such judgement was reported to be distressing, humiliating and eroding trust. The relief at diagnosis (which was delayed in all cases) was tangible as the implication that they were frauds, malingerers or psychologically impaired was quashed.

I was told that the blood tests weren't showing it, .. sometimes you could enter the clinic and you are ravaged by the pain, not much showing on the blood test and other people who the blood test says they should be ravaged with pain aren't! So that was the problem that I faced at the time.. It was a nightmare for me, half the time I had people saying, 'Oh this must be awful for you', and half the time others saying, 'Well maybe you don't really have it anyway' [P24 Catriona]

there was relief [upon diagnosis], I wasn't dying, I was thinking it isn't all in my head, maybe the doctors think it is, maybe its psychological, and I just knew, I just felt so different. I couldn't wear my shoes or my rings, I just felt so horrible.. [P21 Yvonne]

Although Catriona (P24) reports she is now happy with the care she receives from a new rheumatologist (whom she considers accepted her pain report at face value, without need for any further justification) there is some suggestion in the text that she feels she 'proved' herself and her pain to the rheumatologist because they had observed periods of 'real' suffering.

It is just in the past two years that I have been really pleased with the help I have been getting.. well, it sounds daft when I've had it for eight years now but, they've [rheumatologists] seen the swelling, they're seen flare ups and you almost feel that you are part of the club now you know? [P24 Catriona]

#### **9.6.3.4 Theme summary**

This dominant theme (Pain as a Conflict between 'Real' Body Pain and Private Pain) was found to pervade diverse pain topics such as reflections of others' pain, patients' own pain experience, the validity of pain reports, interactions and relations with rheumatologists etc. At the core of the theme is the understanding of pain as a complex phenomenon, not directly proportionate to disease but influenced by many factors. However, this conception of complexity is simplified to a fundamental distinction between pain that is related to the body or having an organic basis and pain associated with the mind or psyche; the former holding greater credibility for patients and, in the patients' view, also for the doctor. Despite patients' conviction that pain in RA has an irrefutable basis in pathological processes (Theme 1) its legitimacy must still be accredited by the medical expert and ideally through objective, clinical tests and examination, these being valued as an assessment 'unpolluted' by the interpretation of a patient presenting a pain report. The repeated reference to clinical assessment appears to be a significant shaper of this pain meaning for the patient. When legitimisation fails or is challenged, the patient may feel that their integrity has been called into question, they may doubt their own experience thus patient-rheumatologist interactions may be associated with an array of negative emotions which may threaten to jeopardise the relationship.

#### **9.6.4 Discussion of Patients' Shared Meanings of Pain**

Themes 1-3 were grouped, as the basis of these pain accounts were reflective of dualistic conceptions of pain in western society. Theme 1 ('Pain as an Expected Symptom') located pain as a physical symptom related to harmful biological processes, this being a well documented and established reductionist, medicalised concept of pain in studies of those with and without chronic pain (May et al, 2000; Osborn and Smith, 1998; Aldrich and Eccleston, 2000). Previous studies of pain in RA have failed to make in-depth exploration of the patient's explanation of pain and are, in any case, dated (Locker, 1983; Bury, 1982). Others use methods which only establish that pain is an expected symptom of RA (Ailinger and Schweitzer, 1993; Kay and Punchak, 1988). These qualitative findings suggest that, similar to lay conceptions of OA (Price et al, 1983), RA is perceived to be a chronically painful and progressive condition, which would worsen with time and potentially be compounded by the effects of ageing (Dickson and Kim, 2003; Sanders et al, 2002). These beliefs appeared to be reinforced through knowledge that medically, RA is not fully understood, nor is there a cure or definitive control. This 'mystery' dimension of RA was alluded to in Locker's (1983) study. It was, however, anticipated (by this author)

that these dated views would not be as prevalent in a contemporary group in light of significant medical advances in treatment of RA over the past 20 years (Fries, 2000; March and Lapsley, 2001). Patients' accounts did not reflect a positive opinion of RA treatment but, rather, emphasised the lack of medical understanding of RA. Similar, limited patient expectations about the effectiveness of medical treatments for arthritis were documented in a small US study; although the nature of participants arthritis was not described (Lambert et al, 2000). Comaroff and Maguire (1981) proposed that there is a threat posed by the inability of doctors to give definite answers to important questions from the individual searching for meaning, given general advances in clinical medicine. This as an explanation may contribute to the accounts given by the interviewees, in addition to their own day-to-day experience of pain.

Whatever the influence, be it social, cultural or experiential, the implications of expectation of pain and the worsening of pain with disease and ageing are significant, carrying the potential to reduce hopes of effective treatments and potentially diminish demand for this. Patients' beliefs in the inevitability of pain (or fatalistic pain beliefs) are recognised as barriers to pain reporting for patients with cancer (Ward, 1993). This may be more pronounced in later stages in RA, as older people are known to attribute symptoms to ageing and thus delay seeking medical care (Leventhal and Crouch, 1997, p82), with some accepting severe health problems as 'normal' (Brouwer et al, 2005). Several older people with RA suggested that their pain would be compounded by age, suggesting that older patients may potentially be more vulnerable to under-reporting pain, an area that warrants further exploration.

'Pain as a Useful Signal of Body/Mind Stress' represents a rare, positive account of pain in RA in contrast to other pain studies of RA which focus upon the negative impact of pain (Bath et al, 1999; Brown and Williams, 1995; Nemchand, 1997). Again, in this study, this theme emphasised the perceived association, or causal relationship between physical body harm and pain e.g. pain due to exercising. However, the positive, protective function of pain was evident, where pain was attended to and acted upon to prevent further pain provocation or potential harm. This finding is similar to references to pain as a homeostatic mechanism enabling the individual to self-regulate action and behaviour (Aldrich and Eccleston, 2000). Although accounts of individuals adapting activities to reduce/avoid additional pain were found in other studies, all (with the exception of Kugelmann, 1999), omit reference to patients' understanding of how emotional and psychological factors could influence pain. This is because they focus upon patients' stories of what they experience rather than exploring the beliefs,

views etc. which underpin their actions (Johansson et al, 1999; Locker, 1983, Shaul, 1995). Although patients demonstrated a wider understanding of pain and how to adapt to it, this knowledge/understanding appeared only to be acquired after years of trial and error, rather than through being formally assisted by any pain-specific education. The education sessions attended by six patients in this study were not pain focussed but attempted to cover a wide range of issues e.g. welfare, drugs etc. This might explain the lack of distinction noted between those reported they had and had not attended RA-educational sessions. Non-pharmacological interventions for pain e.g. patient education about coping, are known to enhance self-management (Robbins et al, 2001; Simon et al, 2002) but provision of these types of interventions are dependent upon hospital resources and are labour intensive (Evers et al, 1998; Superio-Cabuslay et al, 1996). [It was notable that only one of seven different regional hospital sites visited for rheumatologist interviews provided multi-disciplinary education sessions for newly diagnosed patients with RA].

Making a judgement about the credibility of pain, through reference to perceived causes of pain in RA, is at the heart of theme 3 (Pain as a Conflict between 'Real' Body Pain and Private, Subjective Pain). This dominant theme pervaded a range of pain topics. Patients strongly identified with the 'real' and organic basis of their pain experience but; as was alluded to in theme 2, it was acknowledged that pain could be influenced by non-physical factors e.g. mood. Pain related to disease or organic factors was considered to be a legitimate pain and was differentiated from pain associated with the psyche or mind. This dualistic, reductionist conception of pain, reducing pain to a defined cause, e.g. joint damage, is characteristic of biomedical conceptions of pain, prevalent in western society (Morris, 1991). In addition, as shown in other studies, pain attributed to biophysical processes was afforded greater kudos than pain attributed to the psyche (Bendelow, 2000).

In chronically painful conditions without definitive diagnosis, patients commonly report conflict with doctors; reporting feeling misunderstood and discredited when their pain is not legitimised as being 'real' by the medical expert (Rhodes et al, 1999; Werner and Malterud, 2003). Similar issues were not anticipated in RA as the diagnosis characterises the illness as chronically painful (Dessein et al, 2000) and there is scant reference to clinical issues of legitimacy in the RA literature. However, patients *themselves* appeared to question the legitimacy of their own pain experience and defer to the doctor's interpretation of pain, rather than assert their own pain experience as valuable and relevant to their care. Patients wanted to have their pain validated through 'objective' clinical measures linking pain to disease activity (e.g. ESR), again, not uncommon in undefined

conditions (Kugelman, 1999; Rhodes et al, 1999). The basis of valuing and placing reliance on clinical monitoring and testing of the body is grounded in the cultural history of medicine, where the body is 'read' and inspected for what it can reveal (Atkinson, 2002, p19). This may explain the finding that patients lack confidence that their own pain experience is legitimate in its own right and this view appeared to be further strengthened by patients repeated exposure to clinical testing/examination at consultations. This is supported by studies which report that patient-doctor interactions strongly influence patient understanding of illness (Brown, 1995; Skelton, 1998; Waitzkin et al, 1994). Overall the legitimacy issue relates to and enhances the patients' notion of the importance of monitoring/assessing disease processes and they therefore appear to identify disease management as the primary focus of clinical assessment and treatment in RA (inter-relating with Theme 7).

Not only does this theme bring to the fore the issue of legitimacy of pain in RA, it is also relevant to clinical care. Patients appear to demote and devalue pain experiences that are not 'real' or 'of the body' in comparison to those that can be otherwise linked to the disease. They may then discount pain as irrelevant to clinical care when disease indicators and their own evaluations do not relate to pain experiences. This could be problematic in RA where measures of disease activity sometimes only explain a relatively small variation in pain intensity (Flor and Turk, 1988, Smedstad et al, 1995; Coster and Bengtsson, 2001). Patients' conception of pain in RA parallels an acute, nociceptive model of pain that is not applicable to their experience of psychosocial factors strongly influencing pain (Sharpe et al, 2001; Young et al, 2000). This is supported by Barlow et al's (2002) study of 15 patients with RA, none of whom could recall receiving any information about pain or disease flares or advice about psychosocial issues.

## **9.7 CONSEQUENCES OF PAIN IN RA – PATIENTS' VIEWS**

The 'consequence' accounts of pain in RA are characterised by the personal nature of talk about the lived experiences of pain e.g. the practical implications of the pain experience for the individual, and the wider impact upon their family (Bury, 1988). Three key themes were identified:

Theme 4 - Pain as a variable disruption of life;

Theme 5 - Pain overwhelms and engulfs - threatening self and body; and

Theme 6 - Pain as prolonged suffering.

The first theme gives account of the ways in which pain is perceived by patients as interfering with daily life. This topic is common in RA literature, although many studies address the consequences of the illness as a whole rather than considering pain alone (reviewed in Chapter Four). Themes 5 and 6 represent dimensions novel to pain-RA literature, these address distinct stages of the illness and its associated pain experiences i.e. pain meanings related to 'flare' and pain meanings in the later stages of illness/treatment.

### **9.7.1 Theme 4: Pain as a Variable Disruption of Life**

This theme relates to the ways in which day-to-day pain can interfere with all domains of the individual's life. 'Day-to-day' pain in RA (as distinct from pain in a 'flare' or pain in the late disease stages - Theme 6) fluctuates and the patient can exercise some degree of pain control. Taken as a whole, accounts are reflective of the negative impact of pain, forcing a disruption of life-course relative to their pre-diagnosis state and of their previously anticipated vision of the future. Pain is considered to impact upon valued roles and functions and eventually culminates in challenge or threat to the image of 'self' (i.e. the individual's attributes that are established through social relations, Charmaz, 1983, p170). Accounts include descriptions of the various techniques and strategies used to accommodate or adjust to pain and therefore overlap with sub-themes outlined in Theme 2 (Pain as a useful Signal of Body/Mind Imbalance).

#### **9.7.1.1 Pain interfering with valued functions**

In accounts of the consequences of pain frequent reference is made to pain interfering with a function meaningful and valued by the patient e.g. the loss of ability to hold a new baby (P13). However, the pain experience appeared to become of secondary concern to the patient once the RA diagnosis was confirmed and they then understood why they had pain. The majority of patients turned to focus on living with pain. Andrew (P1) gave his account of how RA affected him in a narrow, defined way and, although his statement is bold, it was a sentiment shared by others. The emphasis being that the loss of bodily function is the primary consequence of RA.

..maybe I'm being unduly hard, but my only reason for having a body is function, to do things with. And whether that is eating food or working a typewriter or walking ten miles whatever.[P1 Andrew]

Failure of the body to perform as it did previously was a common topic and frequently linked to this was an explanation of the significance that the failed performance held for the individual. When valued roles were altered or lost, a sense of who they were as a person was challenged or threatened. Barry (P2) encapsulated the sense of threat to self when he was unable to achieve things that made him the same as other adults in society. Here he talked about needing to be helped to get dressed:

You are in so much pain that you can't do the normal things that you would do for yourself, as a human being. [P2 Barry]

Key areas of function affected by pain were mobility, self-care, work, vocational tasks, recreational activities and domestic tasks. The consequences attributed to pain included: 1. inability to conduct a task, 2. inability to perform a task as normal (i.e. the performance had to be adapted) and 3. ability to perform a task in a normal way but more slowly. The threat of incapacity in self-care tasks and of dependency upon others was of particular concern but the threat was generally associated with the pain of a 'flare' rather than daily, fluctuating pain experiences.

#### **9.7.1.2 The importance of threats to family roles and relationships**

Repeated reference was made to the burden of pain threatening valued roles in family life and relationships. There were no obvious distinctions between male and female accounts. However, men who developed RA in working years and who had to give up work focused upon their failure to provide income for their family. In comparison, women's accounts were focused on concerns about failure to fulfil caring roles for children or related to failure to be a supportive and dependable partner. Older patients were concerned that they were not able to do as much as they had hoped for with their grandchildren but were also concerned about being a source of worry and burden to their own children. In addition, the strain of the invisibility of pain for those around them was highlighted as a problematic issue as well as the inability of others to help them:

it is difficult, it is for any couple initially too because you are in a lot of pain but you can't see anything and a lot of the time there isn't anything to be seen. It's not like having a sore throat or having a cold, it was hard for the kids to understand because they can't see anything. [P24 Catriona]



### **9.7.1.3 Mood, emotion and pain**

Feelings of frustration, anger, irritability and annoyance were common in accounts, often associated with pain when it was perceived to be a barrier to a valued function:

It makes you crabbed [i.e. irritable], it makes you ill tempered at times, it makes you feel down and out, well not down and out, but obviously when you can't do things, and to think what I used to be able to do! [exclaims] I mean I used to work all the time [P9 Ian]

Without prompting, 58% of patients interviewed reported feeling down, low or depressed at some point in their illness. Seven patients (three male, four female) reported a history of medically defined depression soon after diagnosis and had been treated with anti-depressants. None reported current use of anti-depressants for treatment of mood. Low mood was not specifically associated in the accounts with pain experiences nor was it linked with particular examples of altered function or roles but was associated with the overall changed life course due to RA.

### **9.7.1.4 Strategies to manage pain: positive comparisons and adopting pain within life**

Included within this account of pain are sub-themes of strategies and techniques used to accommodate to and to manage pain and its impact. Re-definition of roles and accommodation strategies have already been outlined in Theme 2. In addition to these, the sub-themes - Positive Comparisons and Adopting Pain within Life are proposed. Unlike 're-definition of roles' and 'accommodation' sub-themes, these sub-themes do not involve modification or cessation of actions but allude to 'mindful' strategies or ways patients' report they think about or appraise pain, to locate it as a side-issue and not a focus in life; enabling a life with pain. These strategies are distinct, as they are not associated with avoidance or reduction of pain, rather, they are ways of viewing the world, which enable a less disruptive or threatening perspective of pain to be adopted.

Patients commonly off-set talk about the disruption caused by pain by reflecting upon their relative well being in contrast to others with a different illness or with RA but who were perceived to have a more severe disease. These patients viewed themselves in a positive light compared to others they had seen at clinic. This was the most common account associated with demoting the significance of their own complaints or experiences relative to the suffering of others.



I met this guy at a car boot sale the other week and he had the two sticks and I got talking to him, he is just thirty-eight and he has got it but oh he is bad with the rheumatoid. He was hit with it and now is walking around with these two sticks and I said how old are you and he said thirty eight and I mean I'm sixty two... I am lucky, look at that chap that publicity man.. his daughter has had it and she has had so many operations. [P25 Darren]

Another common comparison made by patients arose from self-appraisal of how day-to-day pain and disruption was relatively less severe and/or disruptive than previous pain experiences, most often referring to their 'worst ever pain experience'.

At the time I couldn't wash myself or anything and I thought I don't want this. And every time I get a mini-flare-up I think back and think positive, it ain't going to be as bad as it was before. [P12 Lyle]

The sub-theme 'Adopting Pain within Life' is described as an acceptance of the inevitability of pain (strongly related to the expectation of pain in RA detailed in Theme 1). This was associated with an attitude of pursuing living and 'normal' valued activities and roles in spite of pain. The patients appeared to accept that pain was inevitable and therefore chose to 'work with it', rather than focus on it. This determined engagement in normal activities appears to reduce the degree of attendance to pain or to the restrictions associated with it:

**Fran:** And whatever you are on [drugs] you are never pain free anyway. **I:** Is that right? **Fran:** well, you are not always in agony but there is always a slight something. Or even it can be things like if someone bumps into your arm or your hand is sore. But every time that you have a bad spell you are left with a bit more restriction and aches if you like. But again I just think that well I have to get on with it. Right now, I know what it is; I can accept it and get on with life.. [P6 Fran]

#### **9.7.1.5 Theme summary**

The impact of pain on life is significant in RA, disrupting day-to-day life in many ways, physically, emotionally and psychologically, not only through patients concern for themselves but including the impact upon family, friends and colleagues. Ultimately, the most often reported threat, from pain, for the individual, is that to valued and meaningful roles, essential in shaping the individual's sense of self. The extent of this threat or erosion of self is dependent upon a variety of factors: age, perceived responsibilities and the personal capacity to use strategies to accommodate and adapt to pain. Thus, the degree of life disruption is always relative or unique to the individual.

## 9.7.2 Theme 5: Pain Overwhelms and Engulfs - threatening self and body

Theme 5 relates to pain experiences associated with a 'flare', where pain was characterised as being acute and overwhelming, incapacitating the individual as distinct from their 'day-to-day' experience of pain which varied and over which some control was possible. Fear and distress were associated with this 'flare' pain experience and this related to the quality and duration of pain sensations and consequent loss of independence. These episodes of pain were related to the disease being active and were expected to have a natural 'end point' as the course of the disease fluctuates naturally. Medical help was sought by some to hasten pain relief.

### 9.7.2.1 *Pain of the body and suffering*

Eighty two percent of patients made a clear distinction between pain states in RA i.e. day-to-day pain and pain experiences of a 'flare'. Consistently, patients described the pain of a 'flare' to be intense or severe, often widespread and unremitting. The sensory dimension of pain was noted to be intense such that it could not be ignored or side-lined but filled their consciousness - the body could not be ignored. This pain state was related to the natural fluctuating course of RA i.e. an increased disease activity along with associated stiffness, fatigue and raised measures indicative of inflammatory activity. The term 'flare' was learned from GPs, rheumatologists or other health professionals who had used it at consultations.

.. a flare is just a devastating attack; it's just as if you have been hit by a cruise missile. And you can't move your body because each joint is just so stiff and sore and each one is just a huge mass of pain. [P1 Andrew]

Associated with pain of a 'flare' was significant disruption of capacity to function, tending towards loss of independence and corresponding increasing dependency upon family or friends for support and care. Suffering is defined as a threat to the integrity of self (Cassell, 1982) and accounts of overwhelming pain were associated with temporary, sustained threat to the integrity of self through loss of what they normally expected of themselves. This state was also associated with fear of increased lack of control since the individual could not control or abate the experience. This led, also, to them feeling isolated by their pain, as others could not know how it felt.

.. it was the feeling of not being in control.. and no one in the house knew what was going on with me. It was just a terrible time and I have never ever been so frightened.. [P17 Sarah]

**James:** But no one realises rheumatic pain, it's the most horrible pain in the world... I had never had anything like it before.. it is excruciating, it will not leave you, it doesn't nag you like a toothache, its worse than that, it just grips you. It's excruciating pain, you just can't imagine it. Everybody seems to be saying things wrong to you and nobody seems to say anything right... And it looks like you are looking for an argument all the time, that's how bad it is, it changes your personality completely. You are a changed man completely. [P10 James]

### **9.7.2.2 Seeking medical help**

Patients tried to moderate their pain independently with analgesics and NSAIDs hoping for a spontaneous resolution. However, when pain was prolonged and failed to abate spontaneously, the individual felt compelled to seek medical help, desperate for any degree of symptomatic relief and associated improvement in function. This desperation to achieve relief from pain is accompanied by lack of concern about any adverse effect medications may have. Patients relied upon their own past experiences of flare to estimate how long the episode would last, using this to evaluate how long it may take to 'wait out' the flare. This 'waiting' for resolution was partly related to the known difficulties of accessing a rheumatology review appointment at short notice. This period of time varied between patients, from a few days to weeks or months, but was always cloaked in an air of uncertainty, as the disease course was believed to be ultimately unpredictable. It was anticipated that in these circumstances doctors would be able to moderate the patient's pain using symptomatic treatments e.g. corticosteroids, this belief being usually based upon past experience.

.. well, I didn't expect everything to go at the same time, it wasn't funny at the time, trying to get to the phone, Oh God. When I got to the doctors he said, 'If I can get you into the hospital will you go?' I said, 'I don't care where you send me, anywhere as long as I get rid of this pain'. [P15 Peter]

.. at that stage if they had said, 'I will give you an injection to put you to sleep' I would have taken it; that was how bad it was. As I say the pain was all over, my ankles, my feet, my knees, my shoulders, my wrists, it was a difficult pain to describe... I was completely floored. [P14 Nan]

There were no patients in the sample who considered themselves to be in a 'flare' state at the time of interview, although, at the time of member check interview by phone, one patient [P26] was. Her account of her experience was used to help confirm the characteristics of the sub-themes (which were relatively well developed at that stage of analysis).

### 9.7.2.3 Theme summary

The overwhelming pain experience associated with a 'flare' or increased disease activity is defined by the intensity and unremitting nature of the pain sensation which renders an individual dependent upon others for care and pain relief. This harrowing emotive experience is associated with fear and distress and is also strongly related to disease processes causing patients to seek medical attention for the alleviation of symptoms when they find that self-directed attempts at pain control are inadequate.

### 9.7.3 Theme 6: Pain as Prolonged Suffering

This pain meaning is generated from the accounts of five patients (P1, P3, P7, P15 and P18; see Table 9.7.3) and is related to the characteristics of the pain experience, the consequences they describe along with their perception of the lack of effective medical control available for their disease and pain. Daily pain was viewed as being relatively persistent and severe (in comparison to previous pain states) and, similar to a flare, presented a threat to the integrity of self, the suffering being viewed as almost a permanent state. These individuals considered that the medical options for controlling disease and pain had been exhausted and that their only hope was a medical breakthrough.

**Table 9.7.3 Characteristics of Patients whose Accounts Generated the Theme: Pain As Prolonged Suffering**

Code/name	Age (yr.)	No. Yr. diagnosed	Self-rated functional status*
P1 Andrew	66	26	III/IV
P3 Carrie	76	32	III
P7 Gwen	87	37	III/IV
P15 Peter	57	3	III
P18 Tess	65	15	III

\* ACR 1991 classification (Hochberg et al, 1992, see Appendix 9.1)

### **9.7.3.1 Persistent pain and prolonged loss of a valued self**

All of these five individuals described their daily pain experience as being persistent and severe relative to pain sensations in earlier years of illness (with the exception of Peter who had only been diagnosed for 3 years and reported never having any relative relief from pain). As in accounts of consequences of pain in a 'flare', persistent pain was associated with significant life disruption, to the extent that pain succeeded in devaluing the individual's sense of who they were and what they could expect to be, devaluing their image of self. Although none of the five rated their global functional status as remaining at grade IV (i.e. limited in ability to perform self-care) all considered themselves significantly disabled having problems with general mobility and requiring daily care/support from others. Their vision of the future was not positive, they foresaw that their pain and incapacity were unlikely to improve and that their own best efforts to manage pain were fruitless. They talked about dealing with each day at a time, not looking forwards.

I don't have any good days. In the mornings I am very, very stiff and it hurts to get up and to get dressed. But there are certain things that you get frustrated about...I can't put my clothes away, I can't raise my arms and put things on the hangers. .. But every day is the same, you know.. As long as I'm sitting, I'm managing ok. [laughs, sighs]. I get a bit scared to [go out] in case I get bumped into or knocked over, well you are hiding away really aren't you. [P3 Carrie]

### **9.7.3.2 Control of pain and hopelessness**

All five patients in Table 9.7.3.1 (with exception of P15 Peter) described their disease and associated pain as having got to a stage where pharmacologically the doctors only had limited (and relatively toxic) options left to try. The disease was considered to be out of control. In Peter's case he explained that since onset, the rheumatologists had had difficulty in finding any effective disease modifying medication. He considered himself a 'difficult case'. In short, the participants believed that on the basis of their own experience and knowledge of which drugs had been tried (and failed), it was unlikely that their disease and pain could be effectively controlled. Patients' own attempts to moderate pain were also considered ineffective. The individual had exhausted their resources with regard to their own control of the pain experience. Altogether this presented as a hopelessness that anything could be offered, by any one, to control pain and promote well being and was much associated with fear for the future. How much worse could things get as and when their condition deteriorated further?

I just feel you have got to go on and lead a relatively normal life. It is more difficult now because you feel so bad.. and you don't have any medication to cover you, as it is now. And you feel so bad that you can't be bothered, you know? I would say this has been my worst time, I was fine but suddenly it has accelerated you know? And

there is this black hole and you think what is in it? Joint replacement? Total care? You are hurtling down towards that, without being able to control it. .. Now I feel they [rheumatologists] are going to.., well, the dregs; but I don't like to put it that way, but I think we have tried all the gold injections, methotrexate, sulphasalazine, we have tried it all. I am quite worried because I don't know where we go from here [P18 Tess, aged 65 yr.]

The tenuous hope of a medical breakthrough or gaining access to some of the new, expensive drug therapies for RA was considered by two as being the only hope of relief. The rheumatologists were not blamed for their inability to help further and were not held responsible. Patients believed that the state of knowledge about RA and its treatments was not advanced enough to offer effective solutions (inter-linking with Theme 1).

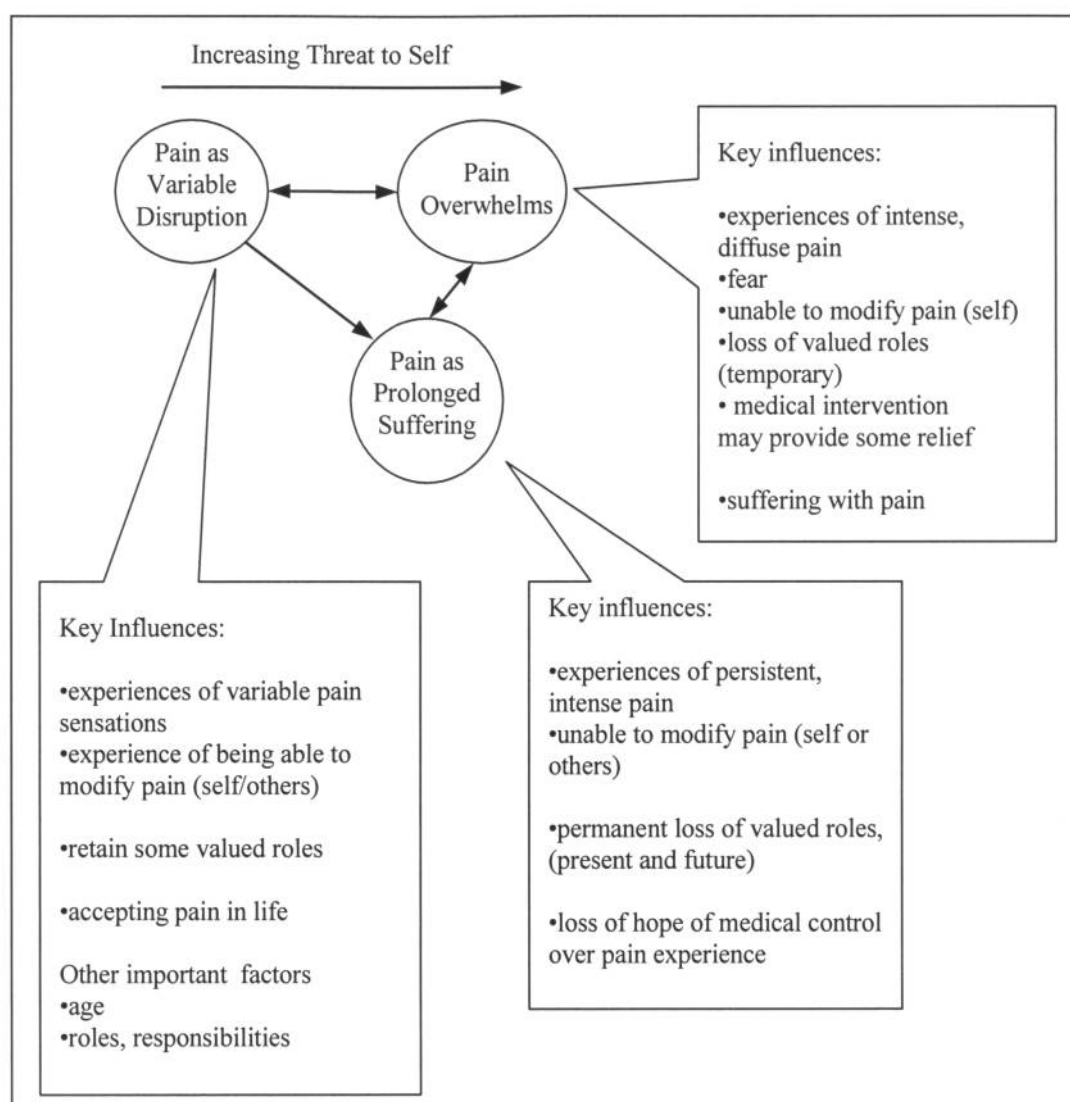
.. they [rheumatologists] have always done their best within the confines of what is available. There was no doubt that I was failing on Methotrexate... the consultants cannot promise what they don't have..[P1 Andrew]

### **9.7.3.3 Theme summary**

Only five patients were found to epitomise these pain meanings although this does not diminish the importance of significant prolonged suffering from persistent pain and the associated erosion of a valued sense of current and future self. This pitiable situation appears to be augmented by a sense of hopelessness in that no one, medical or otherwise, can ease or aid the situation. It appears that they live with a fluctuating negative image of self, which varied day-to-day as they cope or fail to cope, not looking towards the future, which they believe will not bring any improvement.

The fluctuating nature of pain experiences in RA results in individuals moving from periods of relative non-interference from pain (Theme 4), to a flare situation (Theme 5) and visa versa. Those experiencing 'Prolonged Suffering' (Theme 6) could also move into the further, heightened state of flare, a transition that appeared to be a reality for all with RA. Figure 9.7.3 illustrates the key influences shaping and characterising each of the three 'Consequence of Pain' themes and reflects how the individual could move between these throughout the course of their illness.

Figure 9.7.3 'Consequence' Pain Themes for Patients - key influences and characteristics



#### 9.7.4 Discussion of the Consequences of Pain – patients' perspectives

Many studies of chronic pain focus upon patients' accounts of its impact (see Section 4.5.2). The literature relating specifically to RA provides less comparative material as most studies fail to differentiate between symptoms and related effects and do not focus upon pain (Bath et al, 1999; Brown and Williams, 1995; Dildy, 1996; McPherson et al, 2001, Melanson and Downe-Wamboldt, 1995; Nemchand, 1997; Ryan, 1996). The defining feature of this study is the organisation of the work into three related, but distinct ways of experiencing pain in RA. The formulation of three themes, not seen in other RA studies, may arise from the diversity of

sampling employed i.e. seeking those of varied ages, stages of illness and treatment, as well as focusing specifically upon talk of pain. Previous studies have failed to sample as widely as this study does regarding personal or disease variables (e.g. Bury, 1988; Locker, 1983; Ryan et al, 2003b). Although presented as three themes, it should be noted that the fluctuation of pain and the variation in personal capacity to cope and ability to cope with changing situations and circumstances mean that a patient can be in flux between any pain 'state' moving back and forth, day-to-day or week to week. All three themes can therefore, potentially, relate to any one patient (see Figure 9.7.3).

The theme 'Pain as Variable Disruption of Life' represents the perceived impact of fluctuating pain experiences upon every day life. Corresponding sub-themes reflected others' cataloguing of a wide range of valued activities disrupted by chronic pain e.g. mobility, domestic interference (Henriksson, 1995; Howell, 1994; Seers and Friedli, 1996). Similar to work in other chronic illnesses, patient concern in RA relates to the perceived threat to valued roles (Charmaz, 1983). Depression was highlighted as a common consequence and is reported elsewhere (Honkasalo, 2000; Howell, 1994, Kugelmann, 1999, Thomas, 2000). In contrast, feelings of frustration, annoyance and anger associated with loss of capacity to function (and often related to concerns about alienation of the family) appear to be under reported in RA with only brief mention in some studies (Locker, 1983; Melanson and Downe-Wamboldt, 2003; Ryan, 1996). Patients in this study reported this was something they considered they should deal with by themselves, although they were not equipped with any specific advice or knowledge of how to go about this. This is identified as an area for further exploration since negative emotions (e.g. anger) can themselves increase pain (Greenwood et al, 2003).

In this study patients described a continuous need to counterbalance functional interference and threat-to-self by using strategies and techniques designed to manage pain within daily life. Such methods as changing task performance, pacing, planning to avoid aggravating or painful tasks are well documented in RA (Bath et al, 1999; Bury, 1988; Locker, 1983; Nemchand, 1997; Wiener, 1975). The making of comparisons relative to others and self to evaluate contemporary pain was an important sub-theme, which, to date, has received relatively little attention in RA. In the discipline of social psychology, social comparison is the process of comparing oneself, one's status or situation with those of others; negative life events commonly result in social comparison, and may mediate a re-shaping of the individual's perspective (Gibbons, 1999). Among types of change noted are, changed internal standards, re-definition of a construct (e.g. pain) or a change in the individual's values. Thus, both



positive and negative comparisons can cause positive or negative changes (Skevington, 1995, p125-130). In this study, patients were generally found to adopt a positive comparison to others with RA (in terms of illness-severity, disability or distress) and, similarly, made positive comparison with those whose illness was judged to be more serious e.g. cancer. Others report similar findings in RA, suggesting those who make these 'downward' comparisons are more positively adjusted, this being considered a form of cognitive adaptation (Affleck et al, 1987b, Blalock et al, 1989). In a qualitative study Dildy (1996) noted patients used a downward comparison to 'convince themselves' that they were not really too bad, relative to others (p180). In contrast, those with chronic pain of disputed origin e.g. repetitive strain injury, making downward comparisons with those considered worse afflicted was associated with raising fears and concern for the future (Beaton et al, 2001, Osborn and Smith, 1998). Such differences may be accounted for by the formal diagnosis of RA, where patients then have a defined 'disease', and understand that outcome and prognosis can vary widely but consider that they have less severe disease than some others. They may also consider their disease to be less life threatening than for example heart disease. In contrast, those without diagnosis have no such 'standard' or diagnosis to guide their expectations of the future or to allow comparison with fellow chronic pain sufferers.

Internal comparisons of 'worse' pain-state with current pain were common and appeared to be used by patients as a means of cognitively coping with pain. Changes in the individual's personal and internal points of reference are known to influence evaluation of symptoms (Allison et al, 1997). This appears to be prevalent in RA where patients appear to display a tendency to compare themselves favourably with past experiences. This does not appear as an issue in the RA literature reviewed but may have some significance as a barrier to seeking help, for example, through such a thought as, "I'm not as bad as I have been, I can cope with this". This area is highlighted as a potential for further work.

'Adopting Pain within Life' is characterised by a determination to continue with valued activities in life, through acceptance of the inevitability of pain. The psychological construct of 'acceptance' in chronic pain has been developed over recent years and is similar (in some ways) to this sub-theme. McCracken (2004) defines acceptance as being associated with a positive way of engaging in life where, rather than attempting to control or avoid pain, circumstances of pain are accepted as they are, energies then being focused on more fulfilling pursuits. Notably, this is only considered a positive adjustment where the best attempts at control of pain and adaptation have been tried and it should be noted that the 'acceptance' definition is qualified by the caveat -

“does not include resigning oneself to all experiences of suffering” (McCracken, 2004, p6). In contrast, it is argued that, in RA, the best efforts at controlling and supporting those with pain are not realised, and patients’ resignation to expectance and acceptance of suffering is not necessarily the most adaptive, cognitive orientation. ‘Adopting Pain within Life’ may be a positive adaptation to living a fulfilling life in spite of pain, similar to ‘acceptance’ (McCracken, 1998) but its application to the RA situation may not be the best foundation. Shaul’s (1995, 1997) definition of ‘Mastery’ suggests that women with RA ultimately progressed to a stage, where they had become ‘experts’ (p295) at reading their body for signals of impending flares and could adapt appropriately through knowing about the disease, its treatment and the experience of living with it, generally through making use of the physical and emotional support of friends and family. In contrast, this study suggests that patients often did not want to burden others with their concerns, fears or problems and did not share problems. Additionally, this study suggests that patients are not experts in RA or pain management, and this contention is supported in other literature with respect to patients’ limited knowledge of RA (Hill et al, 1991; Minnock et al 2003).

Individual groups identified as being particularly vulnerable to anticipating significant life disruption were those diagnosed at a young age and having dependent families e.g. a young mother or the primary family provider. For younger patients the threat to self and to the anticipated roles and responsibilities relative to their age was immensely significant as they had a longer future to consider in terms of increasing incapacity. They also appeared to be constrained in their efforts to accommodate to their pain through inflexible work practices (Howden et al, 2003), domestic situations or finances or a combination of these factors whilst faced with unpredictable daily symptoms and varying functional capacity. This study suggests that when exploring an individual’s pain-related needs, a focus upon the individual’s personal circumstances, ideas about their ideal/current roles and responsibilities and their concerns about the future may provide an additional useful insight into the management of RA.

The theme ‘Pain Overwhelms - threatening self and body’ is a rare account of the emotions and degree of disruption associated with an exacerbation of the disease: a ‘flare’. The fluctuating nature of pain in RA and the recurrence of periods of intense and incapacitating pain is a surprising omission in other RA accounts. The distress and fear of an anticipated flare are under-reported in RA and may relate to the tendency of the patient to talk about their day-to-day pain or the self orientation of interviews to the description of the most common pain experience together with a lack of focus upon retrospective pain narratives. Only two RA studies directly refer to

the fear and uncontrollability associated with severely painful episodes (Locker, 1983, Shaul, 1995 and 1997). The consistency of patient description of experience, emotions and vivid memories of flares marked this as a significant experience. The body being consumed and incapacitated by pain is similar to accounts of acute pain experiences e.g. burns pain (Morse and Mitcham, 1998). However, unlike the patient with acute burns pain, who is treated in hospital, the individual with an acute RA flare is at home, awaiting natural resolution and/or attempting to modify their medication to self-manage their pain independently. Those few patients who reported having access to Helplines at their hospital rheumatology department reported these to be invaluable at such times through gaining immediate expert advice and possibly also an emergency appointment. This is supported by others' findings that good access to rheumatological services is considered important by patients (Ahlmén et al, 2004). The majority felt limited in their ability to gain such immediate attention, the route from GP to consultant generally being long in terms of time. However, when pain persisted past the point of expected resolution patients did seek help. The risk of this behaviour i.e. delaying seeking help, is that continued suffering with acute, severe pain is known to sensitise the pain systems and presents as a risk factor for pain chronicity itself (Jensen et al, 2001). Patients do not appear to be aware of this.

'Pain as Prolonged Suffering' is defined by what patients consider to be a relatively severe and persistent, uncontrollable pain experience which is associated with significant disability, devalued image of current and future self. The loss of coherence of self is adequately represented in studies of undefined chronic pain (see Section 4.5.2.2) but is not emphasised in RA studies. This failure to consider the different stages of illness as an important variable in purposive sampling may account for the lack of comparative work in this area. Similarly, failure to report upon cross-sectional analysis of accounts and the recognition of connections between stories of suffering and stages of treatment may also have affected the historical perspective among previous researchers.

As well as the threat that pain poses to self, the lack of control over pain, such as a flare state was a key factor leading to patient distress. Issues of a sense of loss of control have been studied in depth in RA using control-related psychological constructs e.g. self-efficacy and helplessness (Keefe et al, 2002; Parker et al, 1995; Smarr et al, 1997). At the most basic level, belief that no one can control the pain (self or others) is associated with negative psychological and functional outcomes; however, these studies fail to identify what experiences may contribute to such beliefs. This study suggests that, specifically in RA, concerns about loss of control are augmented by perception that the medical options for treatment are dwindling and those on offer come with

greater risks/toxicity. As I describe in my reflexive notes: “Although this theme is developed from only five patient accounts there is a strong, coherent and repeated reference to knowledge of the stage of medication, options used and remaining, and risks of these”. Concerns about running out of DMARD treatment options has been reported elsewhere, although the particular personal circumstances of this were not developed as this was not part of the aims of that study (Goodacre and Goodacre, 2004). Emotions arising from fear of greater pain in the future, resultant loss of independence, suffering and the hopelessness of attaining any control dominate this theme. Perhaps surprisingly, an individual even at this stage might still attempt to protect family and even a partner from the extent of their suffering; this to lessen their sense of burdening others. The question arises, who can they burden with their concerns and who will offer to support them?

Pain clinics specifically for rheumatic pain are uncommon but those who do run such facilities suggest that, in some cases, patients may require alternative treatment not often offered by conventional rheumatology clinics e.g. pain education, alternative analgesics and testing of opioids (Nisell, 2002). There is perhaps a need for greater support of these patients and future studies could purposively select individuals, who do not ask for assistance or do not make their suffering obvious. To further explore this group (which comprises only a small cohort in this study) individuals might be identified by stage of treatment, perceived quality of life and/or self-rated function. Their support needs could then be explored.

The consequence of living with chronic pain cannot be underrated and neither should the extent to which the individual feels her or her life has been thrown off course or the degree of suffering they endure. Over thirty percent of patients made spontaneous reference to either having suicidal thoughts or reflected that, at some stages of illness, they could understand how someone similarly afflicted might consider taking their life. This conveys some idea of the enormity of the sense of disruption caused by having to live with chronic pain in RA.

## **9.8 CLINICAL-CONTEXTUAL MEANINGS OF PAIN IN RA – PATIENTS’ VIEWS**

Key informant discussions and the literature suggested that experiences at the hospital clinic, interactions with the rheumatologists and beliefs about medical treatments were important factors shaping pain meanings. Mini-research questions (see Section 8.2.6) were used to generate talk about pain in relation to clinical pain assessment, the reporting of pain and interventions. The accounts generated, highlighted the importance of

interactions with the rheumatologist in shaping pain meanings, at the same time emphasising the complexity of patient pain meanings which might negatively influence talk about pain at the clinic. Three key themes were generated:

Theme 7 - Negotiating pain to match perceived responsibility;

Theme 8 - Unacceptability of complaining about pain - maintaining positive relations; and

Theme 9 - Evaluating pain in anticipation of analgesic interventions.

### **9.8.1 Theme 7: Negotiating Pain to Match Perceived Responsibility**

This theme was derived from patients' accounts of the varied and separate roles and responsibilities adopted by themselves and rheumatologists in dealing with pain and its consequences. In essence, the rheumatologist role was identified as being the primary assessor of the 'disease-affected body', their prime responsibility to manage the disease through use of drugs and so to slow disease activity and progression. This theme was built upon the distinction that patients drew between those aspects of their condition which were of relevance to the medical expert e.g. blood test results, and those which were not relevant e.g. the emotional impact of pain. Patients clearly identified and described rheumatologists' role as being disease specific, assessing the patient's body for signs of the disease and then issuing and monitoring medication used to control the disease. The pain experience was a secondary issue in terms of assessment and treatment, in spite of patients' assertions that pain was understood as a symptom of disease (as described in Theme 1). The expectation of pain, fluctuation of pain and the ambiguity of pain (Theme 3), as being something which was 'real' and/or augmented by the psyche or other non-disease factors, further complicated patients' opinion of the clinical relevance of pain. The pain experience of the patient was, therefore, only pertinent in cases where it was viewed by the rheumatologist to be proportional to or representative of disease activity. Such ambiguity was not an issue in circumstances perceived as overwhelmingly threatening e.g. a flare (Theme 5) but was at regular clinic reviews, which most often concurred with non-flare periods. Fluctuating and ambiguous pain experiences and their consequences i.e. those which could not be clearly associated with disease, were seen by patients to be their own responsibility to be managed as best they could by adapting practically and mentally to their situation. [Table 9.8.1 summarises patients' views of their own and doctors' responsibilities regarding pain.]

**Table 9.8.1 Patients' Perspectives on Roles and Responsibilities of Rheumatologists and 'Self' Regarding Pain Assessment and Management**

	Rheumatologists' Responsibilities	Patients' Responsibilities
Assessment	<p>Assess the body for disease/drug effects</p> <ul style="list-style-type: none"> <li>palpating/moving/looking.</li> </ul> <p>Patient's pain report</p> <ul style="list-style-type: none"> <li>evaluate relevance in light of clinical tests and signs.</li> </ul>	<p>Respond to doctors' questions. Offer the body for examination.</p> <p>Patient's pain report</p> <ul style="list-style-type: none"> <li>offer report of pain dimensions which are considered to be associated with the disease - sensory/discriminative information.</li> </ul>
Management and interventions	<p>Manage the disease i.e. slow the disease</p> <ul style="list-style-type: none"> <li>altering drugs</li> <li>monitoring body status</li> <li>monitor drug side effects.</li> </ul>	<p>Manage life - with and in-spite of pain</p> <ul style="list-style-type: none"> <li>utilise own resources (Themes 2, 4)</li> <li>seek support from peers, family, friends (limited)</li> <li>seek support from other sources (e.g. Arthritis Care, for only a limited number).</li> </ul>

The personal consequences of pain were not seen to be rheumatologists' main responsibility, including any emotional, psychological or social disruptions. Consequences of pain which were non-physical or not observable by the doctor e.g. impact upon relationships, were not always presented to the medical expert but were concealed. Managing the psychological, social and emotional consequences of pain or the illness as a whole, appeared to be seen by the patient as aspects of the illness which they should manage themselves. A small group sought support from their GP (P22, P26, P28). Two regularly attended Arthritis Care groups (P13, P21). Talking to friends and family about pain related problems was presented as being problematic (discussed further in Theme 8). Thirteen patients spontaneously reported they would not want to attend 'support group' type of meetings and only three reported having been offered hospital based educational classes about RA, all three attended and endorsed these as useful (P19, P24, P26).

#### **9.8.1.1 The Rheumatologist as an expert assessor of disease**

The main purpose of a clinic visit was viewed as being an opportunity for the rheumatologist to assess disease activity and its effect upon the body. The doctor was credited with being able to determine the extant condition of the body using information gathered via clinical examination, incorporating test and imaging results. Reports of pain were therefore secondary to, or at least only supplementary to, this more objective clinical information.

Patients repeated reference to the necessity for the rheumatologist to have objective test information was interpreted to affirm patients' perception of the relative importance of objective, disease activity evaluation at clinic as opposed to the subjective accounts of pain and its interference with life available from the patient. This also affirms rheumatologists' responsibility as expert manager of the disease and body. Clinical examination of the body through looking or palpating was regarded by the patient as vital, and was associated with the high regard in which the specialist was held. Physical examination was associated with 'good doctors' who would be able to determine and describe what was happening to the body.

I: how do you explain the pain to the doctors? **Carrie:** Oh, I don't really. The doctor at the hospital just says the same as my doctor (GP), 'Your arthritis is very active'. They can tell that from the bloods I suppose. Well, they talk about flare-ups and she [Dr] can see it in the blood. I mean the doctors when they come around they feel your knee and say, 'Oh yes, your knee is hot today' and I suppose they can tell by that can't they? By feeling it? [P3 Carrie]

#### **9.8.1.2 Rheumatologists evaluating the legitimacy of pain reports**

The rheumatologist was regarded by the patient sample as the rightful judge of how well patients' pain report matched clinical information related to disease, using this to determine drug intervention. The rheumatologist was regarded as having the superior knowledge of the disease and understanding of test findings so enabling evaluation of the pain report. This was reinforced through experiences where the patient felt they were improving or remaining stable but testing had implied deterioration, or showed toxicity effects from drugs. Therefore clinical experiences heightened the authority of the medical expert over the patients' own feelings, further relegating the subjective pain experience to being unimportant, an ambiguous experience perceived to have little relevance for the disease-orientated rheumatologist. Examples of the pain experience requiring clinical qualification to determine its degree of association with disease was found in over 90% of accounts, and links closely with Theme 3 related to the legitimacy of pain.

I think a lot of mine you can actually see it, when they [rheumatologists] look at it and get a little bit of history and they know where they are. ... And the other thing is of course x-rays and that is one, which I look at. They do a baseline set of x-rays now, they did it the last time too and you can understand that because that gives them something to work on and blood tests. [P4 David]



### **9.8.1.3 Broader roles in pain management for GPs and nurse practitioners**

Encouraging talk about the different roles and relationships patients had with various health professionals e.g. rheumatology nurses and GPs, helped to clarify patients' perception of the characteristics of the rheumatologists' interests and roles. Most revealing were five accounts (P21, P22, P24, P26 and P28) which all referred to particularly supportive GPs, who provided a personal and empathetic care and support of a type which they did not expect to receive from their rheumatologist. The basis of this empathy and understanding by the GP in two of the cases was that the GP himself had RA, in the other case the GP's sister had RA. This was particularly related to them being more understanding and empathetic, asking about how pain affected them day-to-day and how they managed to cope with everyday activities that were important to them. Several patients identified the rheumatology nurse as a source of non-medical support and advice, a professional with whom emotional and social issues could be discussed (P17, P21). Overall, patients appeared to differentiate reporting problems to the health professionals dependent upon how they identified the role of the listener.

I think I'm just number at the hospital. I don't think he [Rheumatologist] knows me, whereas you go to see the GP and he knows my husband and how many children I have and he knows I'm not a baby and when I say its sore, its sore you know? [P21 Yvonne]

The consultant is there for the disease and not really for anything else like depression, that is for your GP, he can cope with that. All I want to talk to the consultant about is the disease and the medication for the disease. I want to know how they can help in that way. The GP knows you, they are really good. .. The GP does know that bit more about you and so you can talk to them and tell them that you are feeling depressed. I feel that they understand, nothing seems too much trouble for them [P26 Ella]

### **9.8.1.4 Focusing the pain report for the rheumatologist and concealing 'irrelevant' issues**

Associated with the characterisation of rheumatologists' responsibilities as seen by patients, accounts suggested that patients 'moulded' their pain reports in an attempt to align them with what they perceived would be most useful to the rheumatologist. Therefore, the patient's conception of an 'ideal' pain report would be one clearly linked to signs or indicators of the disease and evidenced by clinical or laboratory signs. The medical expert could then validate the legitimacy of the pain. The presentation of pain reports followed on from ideas about what was considered useful to the clinician e.g. giving information regarding the site of pain, intensity, duration etc.



With this type of information the expert is expected to integrate clinical, objective information to 'determine' what is happening within the body.

I don't think that anyone wants to hear this kind of story [referring to him telling his story of pain to the interviewer] for this length of time! They [rheumatologists] don't need to if they are focussed. **I:** What do you think the doctor's focus is then? **David:** Finding out what is going on! It's what they do, there are tests that they can work to do it. **I:** Like blood tests? **David:** Oh yes (PAUSE) but also question tests, like what does it feel like? Is it a hot pain or a sharp pain or this kind of stuff, they ask me this. But I think a lot of mine you can actually see it, when they look at it and get a little bit of history and they know where they are. [P 4 David]

Within pain accounts when talk moved from the personal impact of pain to clinician encounters, narratives also moved from reflection about fear or frustration, to talk of locating pain within the joints and associations with swelling and disease. The patients inferred that what they told the doctor was pre-planned, a summary account of how they had felt since last seen, aligned with what they thought the rheumatologist would want to know, a credible account about issues which could be medical or physical.

.. they can't empathise completely with you no, they can't because it is impossible. Doctors can't know what pain is unless they have suffered it, so you have to sort of tell them basically what the main problem is and see what is the main thing is that can stop it .. [P25 Darren]

You try and let them know how you have been since you last saw them, whether you have been having trouble with this joint or with that one. Eh, it's difficult because you do not get a long enough time with them and so you try and condense it. I focus on main parts, like I have had a lot of problems with my shoulder at the moment but if I was having problems with my knee continually you would focus more on the one that was causing you the most trouble. [P26 Ella]

#### **9.8.1.5 Theme summary**

In summary this theme relates to patients' accounts of a form of negotiation of their pain report or presentation at the clinic based upon their conceptions of rheumatologists' primary interest and role i.e. objectively assessing the body for disease and managing the disease. Clinical tests and measures are held in high regard for being objective tests the experts use which lend credibility to the ambiguous, subjective pain report, helping to discern its relevance regarding disease processes and effects. These accounts appeared to be strongly influenced by clinical experiences of assessment and patient-doctor interactions. Pain reports were fashioned to present a credible, disease related report that was thought to be most useful for the rheumatologist (this was also curtailed to fit within the time for the consultation). In this way patients focussed upon sensory-discriminatory pain details, locating the 'worse joint' site. Consequences of pain which were non-physical e.g. emotional or psychological

were deemed more relevant for the patient to deal with independently, with only a small number seeking support from the GP, nurse specialist or support group.

### 9.8.2 Theme 8: Unacceptability of Complaining About Pain - maintaining positive relations

This theme is identified through accounts referring to the general undesirability of talk or complaint about pain, and more specifically pain reports to the rheumatologist. The undesirability of pain talk or complaint was associated as being something which others did not want to be subjected to, burdening others and thus potentially repelling the listener. An associated negative connotation of pain talk was the dislike of being viewed, by others, as an individual who complains or 'moans' about pain thus labelling them as a complainer. Patients referred to observation of peers' pain talk behaviour as portraying a negative image of people with RA by identifying themselves as being a 'sick' person, which many of the RA patients did not consider themselves to be. The label of complainer or 'moaner' was to be avoided at all costs, as it was not aligned with their own conception of how they appeared as individuals. Patients therefore chose to conceal their pain from friends, family and partners when they were asked about their well-being or pain. In support of this, fieldnotes made by the author read as follows: "Many patients comment after the interview that they would never normally talk about their pain so extensively to anyone and even suggested that it must be an ordeal for me to have to listen to it. David (P4) apologised for his pain accounts: 'You've got an hour today, so you are getting lumbered with it'".

An important facet of this theme is patients' belief that being perceived by their rheumatologist as someone who repeatedly complains is not ideal since the relationship between the doctor and patient is anticipated to be long-term. Patients did not want to jeopardise future patient-doctor relations by repelling the doctor with their pain reports or being identified as a troublemaker or complainer. Ideally the patient wanted to be liked by the doctor, to be viewed as a positive, coping individual who tolerated what they could, not 'bothering' the busy doctor without valid reason:

**I:** you mentioned the doctor asked you 'how have you really been?' Are there things that you don't tell them? **Juliet:** Yes, you don't want to go along and just be one of those people who just moan and moan on. I mean you must have met those kind of people when you just think to yourself, 'would you just shut up'. **I:** so you are concerned about what they have to listen to? **Juliet:** Well, I don't think that they take you as seriously when you just go in and whine and whine on, I think you have to go in and present yourself in a calm fashion and say, well this is the facts. Rather than

just go in and whine on and on. **I:** but if you have never gone in and whined on and on how do you know that is how you would be treated? **Juliet:** Because that is what I would think. I would think, get a grip. ... Maybe it's the way I look when I go in, I don't look miserable. No one likes a moaner and I must come across as being pleasant enough because all the doctors letters say: 'Pleasant lady ...'[P28 Juliet]

Those patients who had experienced sharing talk about pain with peers all reported finding this beneficial, a 'release', as well as feeling understood and possibly gaining practical tips or advice about ways to cope or manage their experience. Only two attended Arthritis Care groups, the majority were averse to the idea of such meetings and not wanting to associate themselves with the 'type' who attends such groups. As noted in the reflexive research diary: "There are strong ideas about the 'types' of people who attend Arthritis Care groups. There is not enough depth/discussion in these accounts to further understand this although this would make an interesting study as it appears to be a barrier to attendance." Accounts of concealing or curtailing talk of pain were not applicable in situations where the pain was overwhelming or threatening self or body (Theme 5).

#### **9.8.2.1 Theme summary**

Talk about pain and the consequences of pain was considered to be undesirable by patients, whether this refers to talk to family, friends, partners or doctors. The reasons for this are mixed, some suggesting pain talk repels others or makes the listener withdraw and it is associated with presenting a negative image of self which the patient generally does not like. In relations with the rheumatologist, it appears patients may consider over-reporting pain could damage relations. They want relations to be positive for fear that in the future, should things get worse, they will require the doctors help and would not want to be disadvantaged by having been labelled as someone who complains without good reason. Sharing pain experiences was only seen to be genuinely acceptable in the interview situation when the pain account was requested and/or with peers and was perceived as a positive experience. However, joining Arthritis Care support groups was generally viewed unfavourably and hospitals did not appear to facilitate any peer support meetings.

#### **9.8.3 Theme 9: Evaluating Pain in Anticipation of Analgesic Interventions**

This theme is defined by its focus on patients' view of medical interventions which reduce painful symptoms, primarily, simple analgesics, compound analgesics and opioid medications. These classes of drugs for symptomatic relief were viewed negatively by all patients. Beliefs expressed included fear of addiction, concern

about developing tolerance and side effects. Overall, symptomatic treatment was perceived to be less important than treatments used to slow disease processes, even when disease-modifying treatment failed to provide substantial pain relief. Associated with concerns about adverse effects, half of patients reported using analgesics as required rather than taking them regularly as suggested by health professionals and some accounts suggested patients may not offer full pain accounts to the rheumatologist to avoid changes being made to their prescription.

Overall, patients reported that they ideally wanted to minimise medication intake of any kind, however this was not seen as a viable option regarding DMARDs prescribed by the rheumatologist. All patients, except one, were using one or more DMARD, the majority taking four or five different types of drug per day. Patients understood that it was necessary to comply with DMARD therapy in the long-term for their current and future health, despite concerns about DMARD toxicity and experiences of side effects from these. The option to reduce drug intake was deflected to the 'pain killing' drugs, which patients understood they could vary. An associated recurrent theme emerged, that managing pain and treatment for it was secondary to managing the disease. This compliments the sub-theme of patients perceiving the rheumatologist to be primarily responsible for treating disease with disease-altering drugs (Theme 7). Concern about and limitation of the use of analgesics was not apparent at times of overwhelming pain (Theme 5) when the patient was willing to accept any prescribed treatment which might provide pain relief e.g. corticosteroids, but these concerns appeared in all other accounts related to pain management.

#### **9.8.3.1 *Patients use of analgesics***

Notably, although accounts of analgesics were negative, patients did not say they were ineffective (only two patients said they found analgesics ineffective). Ninety percent of patients reported that they currently used analgesics with varying degrees of frequency. Fifty two percent of patients reported using compound analgesics (most commonly Co-Codamol or Co-Proxamol), 31% used opioids (e.g. Dihydrocodeine or Tramadol) and 28% reported using simple analgesics e.g. Paracetamol, (21% of patients reported using more than one class of analgesic drug).

### **9.8.3.2 Perceived negative effects of analgesics and limiting usage**

Patients reported fears of addiction or of developing physical dependence on analgesics. This was associated with limiting the use of analgesics whilst admitting this was possibly contrary to advice about more regular use from their GP or rheumatologist. Other concerns included, developing a tolerance to analgesics, which they believed would then limit their effectiveness over time and fear of using up the analgesic options for effective pain relief (believing that if they started using weak opioids and developed tolerance to these, there would be fewer options for pain relief in the future). Ultimately the basis of both concerns was that, faced with an unknown future of pain, diminishing analgesic options for the future was too great a risk to take. Another common concern about analgesics related to side effects, particularly from opioid medications (e.g. sedation and constipation).

This extended excerpt from Moira's (P13) interview highlights her concerns regarding addiction and the potential adverse effects of long term consumption of medications, particularly in relation to her conscious effort to limit the use of Co-Proxamol. She talks about getting information from peers at an Arthritis Care support group meeting, which may contain some grain of truth, but her knowledge of addiction regarding Co-Proxamol is flawed and her two-a-day consumption of Co-Proxamol potentially ineffective.

I've got painkillers, which I am trying not to take, I'm trying to keep for..., well I think they are kind of are addictive. .. And I mean before [before RA] I never used to even have headaches and if I did it was like, painkillers straight away because I thought I'm not having this [laughs]. But now I think, well, 'No, you are going to be like this for the rest of your life and where do you go when you are taking the painkillers all the time?' I: What painkillers do you have? **Moira:** I've got co-proxamol. I: So you tend not to take the co-proxamol on a day-to-day basis? **Moira:** I try not to, I end up taking about two a day. But I can take up to eight a day. I try to keep them for when I really have to take them because..., in the Arthritis Group that I go to they are always talking about their hip replacements and about replacing their joints; like I would talk about having a cup of coffee! A few of them are saying that you know, long term usage..., and a lot of things can cause organ problems and you know like the steroids, and I think well, right enough you know?... there are days when I have to take the painkillers, all of them, but I try..., and take just two or none at all. Because I feel you have to endure some of it. [P13 Moira]

### **9.8.3.3 Pain interventions as secondary to treatment of disease**

The message that disease modifying drug therapies were viewed as the essential treatment in RA had been clearly impressed upon patients who demonstrated knowledge of DMARD names (all the different ones they had used), detail of how they were to be taken, potential side effects and reasons for blood tests to monitor toxicity. Equally patients were all aware of their mode of action i.e. to slow the disease processes. This information had been

presented to some patients at rheumatology clinics by the rheumatologist or for some by the rheumatology nurse, and had been reinforced by written information. The focus of information on DMARD therapy and the perceived focus of the rheumatologists on the prescription of these drugs, when added to patient belief in tackling the underlying cause of pain (the disease, Theme 1) focuses on this treatment and obscures the relevance of all other interventions. David is a rare case, not having ever taken analgesics but his sentiments about DMARD therapy targeting the disease processes rather than ameliorating symptoms is shared with all others.

I have never taken painkillers for it at all .. I think that that it's an attitude thing, because my line is that they [DMARDs] are fixing it [disease], and the pills that you want to take are pills that fix it, not the pills that conceal it [analgesics]. [P4 David]

#### **9.8.3.4 Concealing pain experiences to influence interventions**

There were no references to patients consciously concealing pain experiences directly attributable to concerns about the negative effects of analgesics. However, patients did allude to past experiences when they had concealed their pain from the rheumatologist to avoid drug prescription changes and/or interventions they were concerned about receiving. Patients were aware that their pain report could influence drug modifications, when these were corroborated by other clinical findings. James (P10) talked about how he concealed his pain for years, fearing that he would be advised to have a joint replacement. Finally, after concealing his pain and limited function for several years he reported his suffering, subsequently had a hip arthroplasty which he reported gave him near immediate pain relief and enhanced his quality of life.

It hurts and you suffer for it.. if anyone suffers this pain it is unbelievable and in this day and age! They can send people to the moon but they can't sort this! .. I can't believe it, I suffered all those years, my God I can't believe it... I suffered for years because of my fault, not their fault, I wouldn't tell them the truth, that I was really in agony.. [P 10 James]

Several patients said they under-reported pain when they did not want medications altered, fearing the period of adjustment might have involved increased pain. Others stated that they felt nothing more could be done and so did not report how they felt. Although this sub-theme was found in the majority of accounts it was noted in the reflexive diary: 'Patients commonly withdrew or backtracked from any statements which suggested that in the past they had not told the doctor the 'whole story'. It is unlikely that patients would want to portray themselves as deliberately concealing information from the doctor if they wanted to be perceived by the interviewer as being a 'good patient' '.

### 9.8.3.5 Negative cases: using analgesia confidently

Four negative/deviant cases were identified differing from the majority in their use of analgesics, using them regularly and not hesitant about reporting changed status to their rheumatologist or GP, thus, potentially, pursuing more effective symptomatic treatment. These negative cases were examined in detail for what they could reveal about explanations for the majority (see negative case patient profiles in Table 9.8.3).

**Table 9.8.3 Profiles of Four Negative Cases who used Analgesics Regularly**

Name	Age (yr.)	Yr. since diagnosis	Functional status	Education (yr.)	Work status
P6 Fran	49	10	II	14	Works (full time) Nursery nurse, ex-nurse
P22 Ann	53	2	II/III	16	Works (full time) Health visitor
P24 Catriona	38	8	II/III	11	Unemployed Mortgage advisor
P25 Darren	62	5	III	14	Retired Nurse and drugs-salesman

There did not appear to be any common link between the negative cases regarding their age, length of illness nor functional status although most had spent above average years in education. Common to all, however, was lower concern about the negative effects of analgesics allied to their positive view of the benefits arising from the regular use of such analgesics (most often combinations of different types and strengths). Overall, they demonstrated a more sophisticated level of understanding regarding addiction, tolerance and ways in which they could safely and effectively use different analgesics. Darren (P25), Ann (P22) and Fran (P6) all had medical backgrounds so familiarity with drugs was a likely explanation for their enhanced drug knowledge. Catriona (a mortgage advisor) had attended a hospital based educational series of lectures on pain management. In addition, she explained that her GP had supported her by providing extra information on analgesics and had spent a long period of time trying different combinations of analgesics until an effective drug regime emerged, enabling her to control her pain independently.



It took me a long time to find a medication that suited me, I tried this dihydrocodeine about year four I think and it just wasn't for me. It was too much but now it is just perfect for me, ideal. So I just tried normal tablet form but I find the slow release ones perfect and at bedtime I can add to it and I can sleep. Sleep was a big problem, I was having a lot of problems trying to sleep for the first five years, it felt a long time. The GP, em it was him who suggested it. I take my painkillers and self-medicate, I've got three different types of painkillers, well three different strengths I should say and its up to me to decide what I take. And again I know how many I can take in a day and the maximum dose. So I can take what I need to take. So if all I need is thirty milligrams that's what I take, if I need one hundred and twenty I will take it. You feel, well now how I tune into myself I can sort of pre-empt a flare up, there are symptoms that I know that I can feel and I think, oh no and I can maybe get ahead of it and it helps. I would say that it has made it almost non-existent the number of times that I have had to go to my GP with pain. [P24 Catriona]

#### **9.8.3.6 Theme summary**

Analgesic medications are commonly prescribed in RA and are taken (in various ways) by the majority of patients in the sample. However, against a common backdrop of seeking to minimise medication intake combined with concerns about adverse effects of analgesics, they appear to use the self-regulated drugs in an ineffective way. Patients emphasise the primary importance of DMARDs for treatment of RA, based on knowledge gained at the clinic. They appeared to understand that they should take DMARDs exactly as prescribed, whilst relegating the use of symptomatic drugs as non-essential and relatively unimportant. Even when patients have found the use of these 'non-essential' analgesics to be effective, when the use of DMARDs failed to control pain, analgesics still appear to be the 'last resort' option for fears of toxicity, tolerance and side effects. The desire not to have medications altered or added to may also result in under-reporting of symptoms.

#### **9.8.4 The Impact of the Clinical Environment on Consultations**

Patient accounts suggested that the clinic environment and associated organisational factors influenced what they may or may not say at the consultation. This indexing category was formed in response to repeated talk about observations of the clinical environment where this appeared to have a negative influence upon the consultation. As this was not directly related to any particular theme, but appeared to be influential in all interactions with the consultant, it is presented in this section as an issue likely to affect pain reporting.

Twenty six of the twenty nine patients made unprompted reference to the rheumatologist not having much time to deal with each patient or having limited time to discuss problems. They appeared conscious of the large number of people in the waiting room, creating a sense that the rheumatologist was rushed and/or overworked. Associated



with this, patients reported concern that if they were to take up more than their allotted 10-15 minutes this may increase the pressure upon the doctor or detract from the time available to others.

.. in a way you feel bad because they [rheumatologists] don't have a great deal of time for each patient. They always seem over-worked, there are lots of people in the waiting room and you can sympathise if they haven't got a great deal of time to spend with everyone. [P26 Ella]

The effect of this time sensitivity may be to influence the pain report, as the patient tries to identify and direct the doctor to the most pressing issue (usually a disease related concern e.g. drugs side effects). Patients report concern that the pressure of time may frustrate and tax the specialist and this is a matter they appear to consider when talking about their problems. There is also a possible link with Theme 8, where patients wanted to maintain positive relations with the doctor in the likelihood that a good relationship would be important in the future.

Every time that you go in to see her she has got clinics and her room is packed and I think: 'How does she cope with all of that?'... And the other rheumatologist is giving injections in her lunch hour [exclaims].. So you know, these people are under pressure. And therefore I don't want to prolong the time [taken for an appointment] because I know there are other people waiting... [P 11 Keith]

### **9.8.5 Discussion of Patients' Clinical-Contextual Meanings of Pain**

Specific exploration of pain meanings regarding clinical pain reporting, issues of pain assessment and management is novel in the field of RA studies. It was the lack of attendance to such issues in RA along with the findings from the key informant studies (sections 8.2.4 and 8.2.5) which guided this dimension of the current study.

#### **9.8.5.1 *Identifying responsibility for pain in RA***

Through-reading of individual accounts suggested that although patients stated that their pain report appeared valuable in the consultation this was later qualified (in many cases contradicted) suggesting that pain reports were only of clinical value when they were seen to be affirmed as disease related through clinical testing/examination. This theme inter-relates with Theme 3, where legitimate or 'body' pain is afforded greater recognition than pain ascribed to other origins. In addition, it builds upon this theme via a narrow definition of the rheumatologists' responsibility. This is identified as a 'disease-orientated' responsibility. The rheumatologist was seen as the medical expert with respect to disease activity and drug management, this identification is supported in other

literature (Locker, 1983; Ryan et al, 2003b). Related to this, was the patients' perception that the most useful and relevant clinical pain report was a physical, sensory pain description thus directing the doctor to the most painful joint. It appears that patients have learned from clinical encounters that the pain report should take a biomedical format, supported by clinical assessments/examination. This reinforces the existing view that patients are avid students of biomedical language and procedures from patient-doctor encounters (Brown, 1995; Honkasalo, 2000; Skelton, 1998). They learn how to provide competent, biomedically orientated pain report (Werner and Malterud, 2003). The rheumatologist is then expected to mediate the relation between patient report and diseased body condition through clinical testing and examination, thus reinforcing the patients high regard for clinical testing as a means to legitimise illness (Rhodes et al, 2002). To compound the effect described above patients' awareness of the limited time available for consultation may contribute to their provision of an even more concise and focused report. Patients have been previously recognised to feel that they are being rushed at clinics and that clinics are often busy (Donovan, 1991) but has not been recorded that such patient views might affect the nature and progress of a consultation.

Ultimately the doctor may not be told the patient's primary concerns once the patient has himself or herself decided what is relevant or not relevant, perhaps saving time at the consultation, but leaving the patient with the problem. In this instance, an intention to control symptoms and to improve or, at least, maintain quality of life for the patient whilst involving him or her in the care equation, provides a very difficult aim for the rheumatologist (Scott et al, 1998, SIGN, 2000). Additionally, partial information received from patients only makes more difficult, the already complex clinical work of identifying patient problems (May et al, 2004; Baszanger, 1992; Sadler and Hulgus, 1992). Interestingly, there exists no sense of 'doctor-blame'. Disease is blamed for the presence of any problems arising and patients were highly complementary about the standard of care they received.

Patients identified as having somatisation disorders and those with medically contested diagnoses e.g. fibromyalgia, are similarly found to frame symptoms around a biomedical model, defending symptoms by using medical explanations related to biological cause. This is associated with patients wanting the doctor to accept responsibility for their pain, to identify the cause and deal with it (Rhodes et al, 1999; Salmon and May, 1995; Söderberg et al, 1999; Werner and Malterud, 2003). The opposite appears to occur in RA where the patient assumes self-responsibility for managing the disruptive impact of pain, with little support asked for or expected.

In RA the doctors' role is defined as dealing with disease while the patients' role is to deal with illness. Accepting responsibility for self-management of chronic illness is reported in OA and other illnesses e.g. multiple sclerosis and may relate to idealised models of social and moral correctness, accepting responsibility for returning to as 'normal' a life as possible when faced with a chronic illness (Charmaz, 1983; Kotarba, 1983, p23; Sanders et al, 2002). However, the moral element of accepting personal responsibility did not appear as dominant in sub-themes identifying what was and was not the doctor's role. The medical ownership of disease by the doctor is the basis of authority in medicine (Salmon and Hall, 2003) and is culturally embedded within society and this is reflected in this study's accounts of pain. A lack of any expectation that the rheumatologist should (or could) do something about non-disease pain-related issues was clear. A few patients identified either their GP or the specialist nurse as more appropriate recipients of emotional, practical or psychological concerns, a finding recognised in other studies (Barlow et al, 2002; Ryan et al, 2003b).

Of most concern was the majority of patients who appeared to assume sole responsibility for non-disease concerns and, as discussed elsewhere, did not want to burden friends or family (Bury, 1988; Williams and Wood, 1988) or their GP with their problems. This majority had minimal or no opportunity for contact with specialist therapists or nurses. This may relate to the known lack of multidisciplinary staff resources in Scotland (Gray and Muir, 2002). In short, the opportunities for sharing pain experiences and their related wider concerns with health professionals who might be able to provide support appeared limited.

#### **9.8.5.2 *Complaining about pain as unacceptable***

Patients with RA and others with chronic pain have been documented to consider pain-talk as being socially undesirable, giving a number of explanations for this e.g. not wanting to burden family or repel friends or dampen social spirits (Bury, 1988; Hilbert, 1984; Osborn and Smith, 1998; Thomas, 2000). Similar themes were found in this study. Pain-talk is also related to individuals' concern that complaining about pain may result in themselves being defined as a sick or ill complaining person, a phenomenon related to illness talk in general (Paulson et al, 2002; Radley and Billig, 1996).

Patients concern that pain-talk potentially threatens patient-doctor relations has not been previously documented in RA. However, Goodacre and Goodacre (2004) suggested that patients did not want to discuss their concerns

about DMARD therapy with their rheumatologist for fear that it may impact negatively upon the patient/doctor relationship. Patients did express concern about being perceived by the rheumatologist as a complainer or 'moaner' related to pain complaints thus suggesting a censoring of their pain report to safeguard relations. Patients anticipated the longevity of their therapeutic relationship and their ongoing dependency upon the doctor. Kotarba (1983, p134-135) suggested that patients always have to consider the consequences of pain-talk in relation to the nature of their audience. The basis of this concern appears ultimately to rest upon the patients understanding that the rheumatologist has social power in interpersonal relationships i.e. the power to supply or withhold the means to fulfil the patients' needs and desires (Goodyear-Smith and Buetow, 2001). Although the dominance of the doctors' professional and clinical autonomy has declined over the past three decades (Harrison and Ahmad, 2002) the lay person still regards the doctor as someone who commands respect and correspondingly trusts and relies upon the doctor to guide and provide treatment (Lupton, 2002). The power balance within a patient-doctor interaction still has a tendency to favour the doctor, who has control over medical resources and knowledge (Charles et al, 1997; Goodyear-Smith and Buetow, 2001). In spite of this however, the patient also has a responsibility to supply information during the consultation and to share decision making so to facilitate the addressing of their needs (Buetow, 1998). The findings of this study suggest that the patients may need to be strongly encouraged to present their personal account of pain, their fears and concerns, giving assurance that their report of pain will not jeopardise future relations and/or care.

The cultural background of stoicism in the face of illness or adversity may also contribute to this theme of the 'good' patient not complaining (Charmaz, 1983, Kotarba, 1983, p23). Study of barriers to the management of cancer pain found that some patients believed 'good' patients did not complain about pain (Glajchen, 2001; Gunnarsdottir et al, 2002). Appearing outwardly stoical is considered by chronic pain patients as being an important dimension of successfully coping with pain (Large and Strong, 1997). Patients may have attempted to present a positive or 'well-view' of how they successfully coped with illness within the interview (Patterson, 2003). However, in balance, the generation of negative accounts of pain in this study suggests that patients may not have been consciously attempting to present a 'rosy' picture of life with pain in RA and appeared relatively frank, with multiple stories of suffering and failure to cope.

This theme presents as another potential barrier to pain-talk in the clinical context, raising the question: to who do patients talk to about their pain when they do not want to burden their family, friends or the doctor? Non-sharing

of pain experiences with friends or family have been reported as minor themes in chronic pain narratives (Bury, 1988; Hilbert, 1984; Thomas, 2000). Hilbert (1984) suggests that the chronic pain experience is essentially acultural, there being no socially defined or accepted way of 'being' with chronic pain within our society. Anecdotally, patients said they had enjoyed the interview experience, a rare chance to 'have a good moan'. Being able to talk about pain is advocated by others as providing a number of benefits, such as giving the individual an opportunity to make sense of his/her experiences, to gain peer support and to enable more positive appraisal of their problems (Smith, 1998, p42; Subramaniam et al, 1999).

### **9.8.5.3 Analgesics and pain**

Exploration of the topic of pain relief generated a wealth of consistently negative accounts about commonly prescribed analgesic medications. This represents an insufficiently studied area in RA where medication research has focused almost exclusively upon compliance/adherence issues regarding DMARDs (Goodacre and Goodacre, 2004; Ho et al, 1998; Horowicz-Mehler et al, 2002; Fraenkel et al, 2002; Park et al, 1999). In this study a variety of beliefs about the adverse effects of analgesics were relayed, which accorded with lay beliefs about medication in general i.e. that medications have both positive and negative effects upon the body and that long term use carries risk of addiction and/or dependency (Horne, 1997, p159-163). Patient concerns about analgesics in this study included beliefs about addictive properties and tolerance, divergent from the medical view but representative of lay concerns (Magliano and Morris, 2002; Moreland and St. Clair, 1999).

Medication beliefs are to an extent dependent upon the type of chronic illness and associated prescribed medications. Decisions to take medication are based on a trade-off between perceived adverse effects versus health benefits; where beliefs about the necessity of the medication outweigh concerns about its effect then medications are more likely to be taken (Horne and Weinman, 1999). Donovan and Blake (1992) reported that at least 50% of patients sampled with inflammatory arthropathy limited their intake of prescribed drugs, most often analgesics. This agrees with the findings of this study. As found in other studies patients wanted, ideally, to minimise all medication intake (Goodacre and Goodacre, 2004) and, although they acknowledged that analgesics were beneficial, patients exercised the option to limit intake and so endure pain. This was off-set by their understanding that DMARDs had to be taken long term for their current and future health, this message having

been clearly impressed on them through interaction with health professionals at the clinic. In contrast, analgesics were considered a less important intervention, one that they were able to vary independently.

Patients appear to know more about DMARDs than they know about analgesics. Donovan and Blake (1992) suggested that rheumatologists might incorrectly assume that patients were knowledgeable about analgesics and fail to provide adequate information and guidance. Knowing that patients' perception of health professionals' attitudes shapes their views about the use and efficacy of drugs used in RA (Goodacre et al, 2002; Goodacre and Goodacre, 2004) the bias towards informing, discussing and monitoring DMARDs may outweigh references to analgesics. Lack of reference to, or information provision regarding analgesics may inadvertently diminish any message about the usefulness of analgesics. The emphasis upon DMARD treatment may also be partly responsible for patients' perception that disease management assumes priority in clinical care (Theme 7). In this way, health professionals may inadvertently support the perception that symptom management is a secondary concern to disease management despite the fact that pain is rarely abolished in RA in spite of the best available DMARDs (Katz, 1998; Covic et al, 2000; Hurst et al, 1997).

Studies of patients with cancer and their concern about analgesics reflect those emergent from this study i.e. fears of addiction and tolerance (Paice et al, 1998; Thomason et al, 1998; Ward et al, 1993; Ward and Gordon, 1996; Yates et al, 2001). Those cancer patients who presented negative beliefs about analgesics, along with expectations of pain (as in RA) were found to use inadequate analgesics for their pain levels, i.e. these patients were under-medicated (Gunnarsdottir et al, 2002; Ward et al, 1993). This suggests that there is a potential lost opportunity for health benefit from analgesics due to lack of understanding and knowledge. Further work would be required to quantify the prevalence of these beliefs and to investigate whether there is a relationship connecting analgesic beliefs, pain experiences and analgesic use.

Whether patients censor what they report clinically for fear of unsought action by their rheumatologist e.g. altering the prescribed medications, is debatable. Accounts in this study suggested that this was the case for a number of individuals but not for the majority of accounts. However, it was considered unlikely that interviewees would want to portray themselves as deliberate manipulators of the clinical encounter, concealing experiences from the expert so as to preserve the positive image of self (Miczo, 2003; Radley and Billig, 1996). Patients' evaluation of the risks of treatment for hip or knee OA can act as barriers to seeking medical help even for those

with severe pain and disability (Sanders et al, 2004). Study of consultation interactions could be a more direct and appropriate method of exploration of issues of concealment, comparing observations with patients' private accounts of concerns/fears related to treatment. However, taken together with patients' conception of the rheumatologist as being primarily interested in managing the disease, patients own focus upon presenting what they consider disease-related or legitimate pain, time limits at consultation and negative views of analgesics, it is likely that reports of pain experiences might presently not be considered a priority at consultation.

## **9.9 CORE THEMES AND KEY FACTORS SHAPING PATIENTS' MEANINGS**

As is commonly found in exploration of insiders views of pain, multiple, complex meanings emerge from individuals' experiences, covering multiple explanations reflecting cultural and social understanding (May et al, 2000; Osborn and Smith, 1998) plus others shaped by particular circumstances, time and context (Honkasalo, 2000; Kotarba, 1983). Pain was represented in accounts as a physical sensation and also as something emotional and psychological, an experience that could be private or shared but always having consequences for the individual's body, sense of self and relationships with others. Although the key patient themes (Themes 1-9) were presented separately the degree of overlap and inter-relatedness is evident within each e.g. pain being expected in RA (Theme 1) is related to resignation to adopt pain within life (sub-theme of Theme 4). Core themes represent central issues which are proposed to underpin key themes (concepts central to patients' pain meanings). They sub-serve the key themes and their influence is seen to permeate each theme generated. Four were identified:

- causal attribution of pain to RA, the disease;
- perceived threat to self from pain;
- legitimacy of pain;
- responsibility for dealing with pain.

### **9.9.1 Charting Evolving Pain Meanings**

Patients often chose to start their account of pain in RA 'from the beginning' starting with a pre-diagnosis story of pain. Common to narrative forms, these stories of self-discovery about pain linked evaluation of pain with accounts of actions and consequences (Garro and Mattingly, 2000). Charting patients' pain meanings at different stages of their illness served to emphasise how meanings evolved with time and experience, the pivotal moment



in defining meaning was when the diagnostic label was 'attached' to the illness experience leading to the gathering of new knowledge and understanding about RA. Like all others with pain, patients wanted to find an explanation that was acceptable to them (Hilbert, 1984; Honkasalo, 2000). The case presentation of Barry's (P2) account of pain, from pre-diagnosis onwards, is a typical illustration of the changing significance of pain when pain is attributed to RA, as well as the impact of pain upon life (see Figure 9.9.1). Barry expects pain in RA, he resigns himself to this believing there is a limit to control of the medically elusive disease. Threat to 'self' plays a vital role in him seeking medical help in the first instance, however, after diagnosis, the responsibility for dealing with pain becomes a shared responsibility between doctor and patient. With time he learns to manage his own pain, shoulders responsibility for coping and managing pain day-to-day along with the social and emotional consequences; leaving the doctor responsible for the management of 'legitimate' pain of a flare.



**Figure 9.9.1 A Case Presentation of a Typical Account of Changing Pain Meanings Extracted from Barry's Interview [P2]**

Pre-diagnosis When she [mother in law] said, 'I've got rheumatoid arthritis, oh I'm in pain', I used to say, Ah, you've got a bit of pain; everyone gets a bit of pain'. I thought you treat it like any other illness, you've got a bit of pain, you take an aspirin.

Onset of symptoms - pain as an annoying sensory experience, interfering with function

I went to the doctor with a sore shoulder.. And he said, 'I think you've got, they call this a frozen shoulder and it's to do with your job'. And I said fine, I accept that, because I'm not the expert. And he said take painkillers.. So I took them and the shoulder was a bit better and so I went back to work and it started again. So went back and he said yes, it's still the frozen shoulder symptom, so we will increase the dosage. And then it settles it again

Symptoms worsen, getting a diagnosis and initial expectations

it wasn't my normal doctor, ..And he said, 'Oh I think you have arthritis, so we'll take some blood samples and send it away'. So I come back and he says, 'its arthritis!'. I thought it could be very clearly controlled. I thought they would give me something to stop this and I would be back at work, earning and supporting my family..

Learning about pain in RA

And then I get other places, sore knee, sore ankle, sore shoulder again... What's going through my mind is, 'what the hell's happening here?' So you go back to your doctor again. And he goes, 'oh this is just flare-ups, you get flare ups, we'll give you this'. So they give you anti-inflammatories, so it calms down again and then it pops its head up again. Somewhere else.

Learning to live with the pain - own responsibility

it's finding a way to get yourself out without giving yourself severe pain and extra strain, if there is a push down handle that is easy you, use your arm, if it's a turning handle, its difficult. If it's a heavy door, it's difficult. But you learn ways round them.

Daily disruption from pain

You can't do things...[sighs] pain is annoying because it stops you doing things that you enjoy doing and you have to stop and think before you do things. 'If I do this will it give me more pain?'.. You have to plan ahead.

Learning about the medical treatments - there is no definite control

My general feeling is that if the rheumatologist says, 'We are going to try you on this drug, we are going to give you this'. Well obviously you think it will work? But you don't know, because there is no magic cure, unfortunately, no magic one. So I will try it, I will try anything to make this less than it is.

Flares and seeking treatment - 'real pain'

There is nothing they [rheumatologists] can do about it until you go in there and say, 'I am as stiff as a board, as an iron board'. Then they will do something, and you want something done about it. I think that their time is precious and I think they have done a good job so far.

Resignation to accept and adopt pain within life

But the more you learn about it the more you realise there is no magic cure and you accept it and you learn to live with it but the pain stops you doing what you used to do.

Interviewer: Is there pain there all the time?

Barry: yes, constant.

Interviewer: How do you deal with that?

Barry: How do I deal with it? I accept it. Pain is pain, and you have to learn to live with it.

### **9.9.1.1 Attribution of pain to RA - playing down the significance of pain**

Unlike patients with medically undefined chronic pain, who continue to search for an acceptable and credible explanation for pain (Honkasalo, 2000), the patient with RA appeared to stop seeking further medical explanations after diagnosis. Locker (1983) suggested patients continued to make attempts to understand pain fluctuations. This study suggests medical explanations given about the cyclical and chronic nature of RA and the likelihood of flares provide the basis of patient understanding, this being supplemented by their own experiences of pain as it varies with activity, mood change etc.

Attribution of pain to disease was key in shaping expectation of daily pain, pain which could progressively worsen with disease progression and ageing, associated with incomplete medical control and understanding (similar to lay conceptions of OA; Dickson and Kim, 2003; Price et al, 1983; Sanders et al, 2002). Accordingly, unlike the persistent demand for medical attention to relieve suffering as occurs in undefined pain (Kugelman; 1999; Walker et al, 1999), those with RA seemed to be resigned to pain in some degree, this potentially acting as a barrier to seeking help (Sanders et al, 2004). Accepting that pain will be a feature of life, something that has to be lived with and integrated into life can be seen as a valuable, adaptive way to cope with pain (McCracken, 1998; McCracken et al, 2004). However, some accounts of pain in RA point to a contradiction where the connotations of pain are trivialised compared to the consequences of pain causing significant daily disruption of life and posing a threat to a valued sense of self. Although strategies of adapting and accommodating for pain are commonly classified as means of positively coping with pain (Covic et al, 2000; Scharloo et al, 1998), they are located here within the theme of disruption. This is to acknowledge that modification or avoidance of activities may constitute a form of 'improvement' regarding daily living with pain (Beaton et al, 2001) but paradoxically may also be associated with threatening the integrity of self (Chapman and Gavrin, 1999).

Throughout patients' biographical accounts of disruption are inter-woven explanations both of expectation and acceptance of pain, bound up with the belief that there is little that anyone can do to further control pain. This might well be true if these individuals were knowledgeable about the self-management of pain and medical treatments available etc. However, this study suggests that patients' pain knowledge is limited and, at times, flawed. This corresponds with reports about patients limited knowledge of RA (Hill et al, 1991; Minnock et al, 2003) and about the need for further education in RA required at all stages of illness (Arthur and Clifford, 2004; Barlow et al, 1999; Kay and Punchak, 1988), which was a request heard throughout this study. Altogether, this

suggests that there is an unmet and unrecognised need for support and information regarding pain in RA. Patient education in arthritis and involvement in self-management programmes has been shown to positively effect outcome (Barlow et al, 2000, Niedermann et al, 2004; Riemsma et al, 2003; Ramos-Remus et al, 2000) and pain specific education and coping skills training are effective in reducing pain distress and promoting positive adjustment to pain (Robbins et al, 2001; Simon et al, 2002). It does not, however, appear that RA patients are presently receiving this type of care and support.

### **9.9.1.2 Threat to self from pain in RA**

'Threat to self' is used as a core theme subsuming the themes related to the consequences of pain in RA i.e. pain as disruption, pain overwhelms/engulfs and pain as prolonged suffering. Patient accounts of the consequences of pain oriented around the actual or perceived threat to the integrity of self (or suffering). Chapman and Gavrin (1999) defined suffering as a failure of expectations of self to be matched by current self. Patients described being in a constant state of suffering when experiencing a 'flare', a stage when they perceived their pain was outwith medical and self control.

Abundant reference to suffering is found in accounts of those with undefined chronic pain e.g. through feeling isolated by pain, loss of a sense of a future (Hellström, 2001; Honkasalo, 2000; Rhodes et al, 1999). In comparison, RA studies fail to move towards conceptualising RA as a condition causing suffering (Locker, 1983, Ryan et al, 2003b; Shaul, 1995, 1997). Several potential explanations exist for this, one is that RA studies have concentrated upon the description of pain consequences e.g. limited mobility, without moving analysis to more abstract concepts (e.g. Locker, 1983) and have failed to attend to the existing qualitative studies of chronic illnesses, which use suffering in their study frameworks (Arman and Rehnsfeldt, 2003; Charmaz, 1983). The second explanation is, that unlike patients without an affirmed diagnosis (who may savour an opportunity to talk about their medically unrecognised suffering; Werner and Malterud, 2003), the patient with RA may choose to portray a positive image of a life that is relatively 'normal' (Cornwell, 1984). In this study, the topic of pain was the focus of probing questions about past pain experiences, reflections upon future pain etc. The use of a heterogeneous sample group was suited to generating diverse pain accounts. Suffering with pain in RA would appear to be under-represented in current RA literature based on these findings, particularly for those individuals

enduring or even anticipating enduring 'flares' as well as those experiencing uncontrolled, persistent pain in the later stages of illness.

### **9.9.1.3 Legitimacy, responsibility and pain in RA**

Issues of legitimacy (Theme 3) and responsibility (Theme 7) have already featured as key themes and discussions presented in sections 9.6.4 and 9.8.5.1 respectively. These are identified as core themes as their influence extends to all other themes. The patient appears to base actions upon evaluations of the probable cause of pain i.e. the body and the disease versus 'other' factors e.g. psychological or emotional factors; where the latter are deemed less important. On the basis of this evaluation identification of responsibility is made, to self manage or seek medical help, the medical expert being involved when disease is identified as the cause (e.g. during a flare).

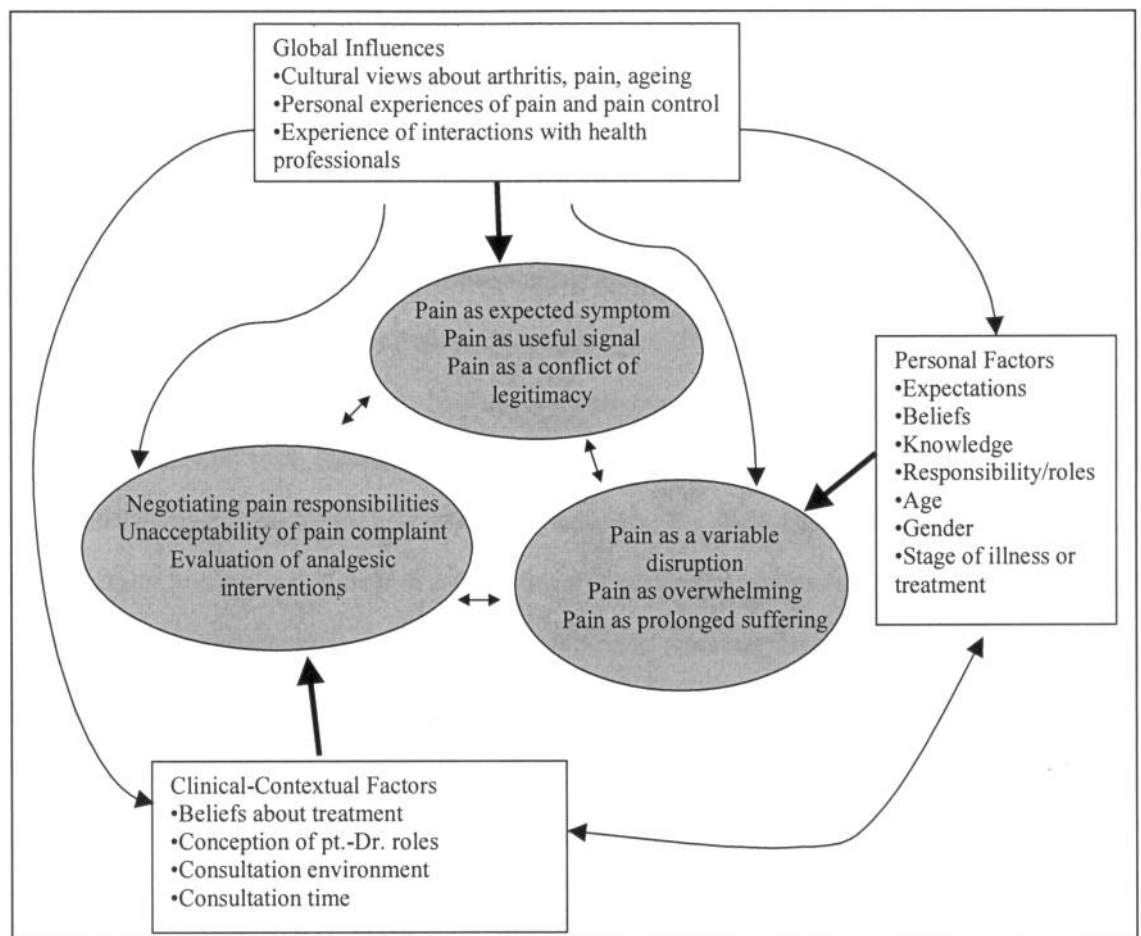
The most notable point about these two core themes (other than their novelty within existing RA literature) is that unlike patients with undefined chronic pain, who perceive that the legitimacy of their pain is questioned by others (Kugelman, 1999; Seers and Friedli, 1996) in RA, it is patients themselves who appear to question the significance of their pain. Ultimately they lay blame for pain and consequent suffering at the door of the disease itself and not with the doctor. Salmon and Hall (2003, p1972) proposed that the concept of 'disease' provides a common enemy, enabling both doctor and patient to escape responsibility for suffering, together fighting against a 'malign entity'. In these accounts the patient appears to bear the bulk of the burden of pain, having little expectation of wider support from medical or other sources. This is counter to the aims of professionals engaged in the management of chronic illness and chronic pain (Gray and Muir, 2002; Simon et al, 2002; Von Korff et al, 2002).

The patient is seen to devalue the relevance of his or her own personal meanings of pain, both inside and outside the clinical context. The primary meaning of pain as a symptom of disease appears to dominate other meanings, such as pain being repellent to others, pain provoking fear and pain threatening self. This study provides support for the argument that the dominant discourse of pain in RA is strongly shaped by the influence of scientific/medical conceptions of pain pervading western culture. This shapes available explanations and understanding of pain in addition to the interactions with health professionals (Morris, 1991; Price and Cheek, 1996). In turn, this may act as a barrier to the expression of other meanings of pain at the heart of suffering, a barrier to the eventual provision of support when need is not relayed to those who could support the individual.

### 9.9.2 Key Factors Shaping Patients' Pain Meanings

Numerous factors interact to shape the meaning of pain for patients with RA as is the case with any personal or subjective meanings (Locker, 1981). Figure 9.9.2 illustrates the main factors shaping the key themes identified in this study.

Figure 9.9.2 Key Factors Shaping Patients' Pain Meanings



Western cultural ideas and explanations about pain and arthritis pervade the interview accounts as well as socially available, lay beliefs about analgesic medications and symptom change with ageing. This is not surprising, as society and culture provide the basic resource through which individuals form explanations (Aldrich and Eccleston, 2000; Kotarba, 1983, p59). The relevant point is that acute, reductionist and mechanistic explanations of pain are not adequate to understand the experience and consequences of chronic pain, which extend beyond the

nociceptive processes (Simon et al, 2002, p2). Without specific knowledge and understanding of chronic pain mechanisms the patient is unlikely to either recognise the significance of non-disease pain modulators and consequences, nor be best equipped to manage pain.

Personal experiences of pain are significant 'shapers' of pain meanings, in particular, the impact pain has upon life as an unpleasant sensory, physical and emotional experience. The relevant practice point arising from this study is that a specifically designed focus is required for individual patients, considering their unique needs e.g. the young adult with dependants, those in particular phases of illness – 'flare' or late stages. There appear to be times when individuals suffer beyond expectations and this is not highlighted within extant literature describing the RA experience.

The strong influence of patients' perceptions of how the medical system and healthcare interactions work with and for them (especially interactions with the rheumatologist) was evident in shaping pain meanings. Previous studies have highlighted the importance patients place upon consultations and information supplied by the medical expert, as well as the importance of patients' perceptions of health professionals' attitudes, shaping their views (Kay and Punchak, 1988; Goodacre and Goodacre, 2004). However, there is little reference in the literature to the potentially negative impact this may have e.g. by conveying the relative unimportance of analgesic medication. There is strong indication here that the patient is an able and avid student of all things biomedical in RA, from tests to biomedical explanations of pain. These medical meanings threaten to overwhelm the more personal pain meanings significant to the individual who may thus feel there is no place for personal pain meanings in the clinical context.

### **9.9.3 Strengths and Limitations of the Study**

The unique focus of this study of pain was grounded in patients' concerns from the early developmental stages of study design. This enabled in-depth exploration of a diversity of subjective pain meanings relevant to the individual and the clinician. This chosen method is a departure from the common qualitative route of describing problems of living with pain in RA or from the focus upon positive and negative ways of coping with pain (Locker, 1983; McPherson et al, 2001; Ryan, 1996; Shaul, 1995, 1997). Through the mix of patients sampled and the use of flexible sampling and interviewing techniques to clarify themes through to theme saturation, proved to

be a particular strength of the study. This led to a focus upon particular patient-relevant experiences such as suffering, which had not been previously documented in relation to pain in RA. The consistency of findings across such a heterogeneous patient group lends weight to the credibility of the themes identified and when considered alongside corroboration of the findings by key informants and peers, supports the transference of findings to adult patients with RA, who experience daily pain and attend NHS rheumatology clinics but who did not take part in the study.

The decision to sample from two different regions of Scotland with different rheumatological services and support systems further supports the transferability of the pain meanings described. One caveat is entered here, namely, Theme 6 (Pain as Prolonged Suffering) which is under-developed, since only five patient accounts were used to generate the theme. This group or a larger cohort would require further study to establish the consistency of the theme and to further develop its relevance. It proved difficult to recruit young males (the youngest being 47 years) although several subjects were young when diagnosed and reflected their youthful experiences (P1, P8, P12 and P19 diagnosed at 40, 43, 36, and 34 years respectively). The exclusion of patients with concurrent painful conditions limits the transferability of findings to this sub-group within RA as additional diagnoses and pain experiences are likely to influence personal pain meanings. [Co-morbidities are known to shape the perspectives of those coping with illness (Pound et al, 1998).] Another group not represented are those who are illiterate and studies suggest this is a significant number in RA, for instance up to one in six of the rheumatology patient population for a clinic in Glasgow were categorised as illiterate (Gordon et al, 2001a). These individuals are likely to have received less education and may be less able/likely to acquire valuable knowledge about pain and illness and, as a consequence, may suffer more than those included in this study. This area requires further work. It could be argued that the types of individual who volunteer to participate in research are different to those who do not. However, the congruence of this study's findings with the findings of other studies with respect to 'Shared Meanings of Pain' and 'Consequences of Pain' among other RA and chronic pain groups serves to support the credibility and transferability of the findings to a wider RA population, especially since recruitment methods used in comparative studies were different from those described in this study.

Building on these study findings, the use of a longitudinal study design may provide additional detail about the nature of the transition of patients' pain meanings as they actually experience variable circumstances, such as periods of improvement and/or deterioration. It might not be appropriate or possible to use the interview methods



described in Chapter Eight when a patient is in the throes of a 'flare', but use of pain diaries or audiotaped accounts might be useful in these circumstances. The use of pain diaries, or other means, for the serial generation of findings was discounted for this study as it was considered that the mass of analytical work associated with this additional generation of findings would prove difficult to manage given the study scope and time schedule for completion.

The study's findings should not be generalised to non-RA populations; however, these findings may encourage further study of personal pain meanings among those who suffer from other chronically painful diseases, specifically those for which there is presently no known cure or definitive control e.g. ankylosing spondylitis, lupus.

The themes and associated sub-themes identified in this study are presented as ways of thinking about pain or ways that sense can be made of the phenomenon whilst accepting that meanings are context and time specific (Kleinman et al, 1992b). Themes, sub-themes and core themes are not presented as a means of predicting an individual's action or behaviour. Rather, they are presented as being potential sources for planning action or as a means to explain or make sense of observations made of those with RA (Stainton Rogers, 1991, p230-231). Although the themes are interpretive (shaped by the author), these have been validated by multiple rounds of key informant discussions with patients and rheumatologists as well as multidisciplinary rheumatology professionals. The presentation of patients' quotations also allows the reader to judge the appropriateness of the inferences made. [See also themes advanced in Chapter 11 for comparison of patient and rheumatologist pain meanings.]



## 9.10 SUMMARY OF FINDINGS – PATIENTS’ PAIN MEANINGS

A summary of the key findings is presented here in Tables 9.10a, 9.10b, 9.10c and 9.10d along with recommendations for clinical practice and further research.

**Table 9.10a Tabulated Summary of the Characteristics of Patients’ Pain Meanings and Associated Recommendations for Clinical Practice and Research: shared meanings of pain**

Characteristics of Patients’ Pain Meanings	Support or Action Required	Areas for Further Study
<p>Pain is primarily understood in a reductionist, mechanical way, reflective of a biomedical model of pain.</p> <p>Pain is ambiguous and does not always link with disease.</p> <p>Expectation of daily pain in RA and progressively worsening pain (this may be compounded by ageing). This is related to knowledge about the lack of effective treatments for the disease.</p> <p>Pain of the body (related to the disease) is considered more important than pain of other origins (e.g. pain augmented by anxiety).</p>	<p>Chronic pain education required</p> <ul style="list-style-type: none"> <li>• differences between acute and chronic pain</li> <li>• mechanisms of chronic pain and its modulation</li> <li>• effects of chronic pain and control strategies and treatments</li> </ul> <p>RA education required</p> <ul style="list-style-type: none"> <li>• medical understanding of RA and expectations of pain control with current treatments</li> </ul> <p>Healthcare professionals</p> <ul style="list-style-type: none"> <li>• should validate/legitimise all pain reports as relevant to rheumatological care</li> <li>• assert the value of the patients’ self-report even where there is lack of corroboration from laboratory/clinical tests</li> </ul>	<p>Explore in greater detail whether older people’s pain attributions are different from younger patients.</p> <p>For example: do conceptions of ageing influence patients’ expectations of pain and help-seeking behaviours?</p>

**Table 9.10b Tabulated Summary of the Characteristics of Patients' Pain Meanings and Associated Recommendations for Clinical Practice and Research: meanings related to the consequences of pain**

Characteristics of Patients' Pain Meanings	Support or Action Required	Areas for Further Study
<p>Pain threatens sense of self and causes suffering</p> <ul style="list-style-type: none"> <li>particularly at times of perceived lack of pain control (self or medical control)</li> </ul> <p>Those at greatest risk of suffering with pain</p> <ul style="list-style-type: none"> <li>young adults with dependants</li> <li>those in a 'flare'</li> <li>those who perceive medical control of their disease is diminishing or lost</li> </ul> <p>Pain can be a useful symptom guiding modification/adaptation of behaviour.</p> <p>Patients are self-taught regarding adaptation and accommodation for pain day-to-day.</p>	<p>Support required</p> <ul style="list-style-type: none"> <li>Provide hospital or primary care based education about self management of pain</li> </ul> <p>Healthcare professionals</p> <ul style="list-style-type: none"> <li>should encourage stories of how pain is impacting upon life (rather than only what is offered by the patient)</li> <li>encourage discussion of the personal, emotional and social impact of pain particularly for young adults with RA and for those who may believe their treatment options are dwindling</li> <li>should consider the provision of a means of access for support/advice for those who are experiencing a flare and educate them about the effects of delaying seeking help for severe, acute pain</li> </ul>	<p>Explore in greater depth, patients' educational and support needs for those who perceive they are at a stage of treatment where medical control is lost or nearly lost</p> <p>Explore the specific needs of those who are experiencing a flare, potentially at the time of their flare (perhaps through the use of diary accounts)</p>

**Table 9.10c Tabulated Summary of the Characteristics of Patients' Pain Meanings and Associated Recommendations for Clinical Practice and Research: clinical-contextual pain meanings**

Characteristics of Patients' Pain Meanings	Support or Action Required	Areas for Further Study
<p>Narrow, disease-focused orientation regarding the rheumatologists' role in RA care (i.e. the doctor medicates to slow the disease)</p> <p>The rheumatologist can and should assess the legitimacy and relevance of the pain report (e.g. using laboratory tests)</p> <p>Psychological, social and emotional consequences of pain are not relevant issues for the rheumatologists (they are for patient to manage)</p> <p>Reports of pain and its effects may damage current and future relations with the rheumatologist</p> <p>Misconceptions about the use and action of commonly prescribed analgesics in RA (potentially losing a health benefit through ineffective use and by censoring pain reports)</p>	<p>Education required</p> <ul style="list-style-type: none"> <li>• broaden patients understanding of rheumatologists' role</li> </ul> <p>Rheumatologists</p> <ul style="list-style-type: none"> <li>• where possible/relevant - consider asking other healthcare professionals to discuss/explore non-disease issues with the patient</li> </ul> <p>Healthcare professionals</p> <ul style="list-style-type: none"> <li>• reassurance that pain reports are important and will not damage patient-professional relations</li> <li>• initiate and encourage the personal account of pain and the impact upon life</li> </ul> <p>Education required</p> <ul style="list-style-type: none"> <li>• what analgesics do, side effects, uses, methods of use</li> <li>• elicit patients' specific beliefs/concerns and behaviours regarding analgesics and address these</li> </ul>	<p>Quantify the prevalence of negative beliefs about analgesics and investigate patients use of analgesics and their pain experiences.</p> <p>Consider modification of existing pain medications questionnaires</p> <ul style="list-style-type: none"> <li>• Beliefs about Medicines Questionnaire (Horne et al, 1998)</li> <li>• Pain Medications Attitude Questionnaire (Hoskins et al, 2002)</li> </ul>

**Table 9.10d Tabulated Summary of the Characteristics of Patients' Pain Meanings and Associated Recommendations for Clinical Practice and Research: the influence of the clinic environment**

Characteristics of Patients' Pain Meanings	Support or Action Required	Areas for Further Study
<p>The doctor has limited time to deal with patients' problems, they are busy and pressured and there are other patients waiting to be seen</p> <p>Potential for curtailed or censored pain report.</p>	<p>Health professionals</p> <ul style="list-style-type: none"> <li>• reassure the patient that they have time to listen to their problems</li> <li>• consider the impact of the clinical environment and your non-verbal communication upon the patients pain report/non-report</li> </ul>	<p>Combined study of patients' perceptions of the clinic and patient-doctor interactions along with observational study of the consultation and the clinic environment.</p>

## 9.11 CONCLUSIONS – PATIENTS' PAIN MEANINGS

The nature of patients' pain meanings support what is found in other studies of personal pain accounts related to conditions other than RA, where they are described as being dynamic, shaped by time, place, personal experiences and culture (Kleinman et al, 1992b). However, the pain themes developed from the patient interviews in this study were discordant with themes identified in the literature for those with undefined pain. This was associated with pain in RA being causally attributed to RA disease processes. Patients' understanding of the disease, its treatment and progression, shaped their understanding of pain as being inevitable and progressive and they were correspondingly resigned to the acceptance of pain as part of daily and future life. This account of pain was presented alongside their accounts of the pervasive and disruptive consequences of pain, which ultimately threatened their notion of 'self'. This apparent paradox of acceptance of pain and the experience of pain eroding the quality of life has not been documented before in RA; although, a study suggests a similar phenomenon may be manifest in osteoarthritis (Sanders et al, 2002). This paradox had potential implications with regard to the non-reporting of pain and pain related problems. Why would a patient be inclined to report pain and pain concerns to the health professional when they expect their condition to be painful on a daily basis and worsen with the inevitable progression of their disease?

To compound the potential for patients to consider their pain problems unworthy of presentation to health professionals, patients' accounts of pain regarding consultations suggest that a simplistic, reductionist biomedical view of pain is dominant. Accounts of pain with respect to clinical interactions and care were not reflective of patients' personal accounts of suffering. Instead, patients identified the rheumatologist as being primarily interested in, and responsible for, managing disease processes; the rheumatologist was identified by patients as being responsible for dealing with the 'legitimate' disease-related pain and physical pain consequences. The patient assumed the greater part of responsibility for pain, attempting to independently manage day-to-day pain experiences and consequences.

The relevance of these findings are set against a backdrop of limited patient knowledge and understanding of the nature of chronic pain and its detrimental consequences. Additionally, patients would appear not to have received any formal education/support regarding pain management nor advice about how health professionals could support them in wider ways than simply supplying medications. The patient with a biomedically constricted view

of pain in RA and with expectations of daily pain may come to believe that all that can be done is already being delivered, thus lessening the likelihood that such a patient will report pain concerns and request help.

These findings have direct relevance for both patients with RA and health professionals caring for them and indicate further required work in RA and pain. The need for patient education regarding chronic pain, its nature, mechanisms, consequences and ways to manage these is demonstrated. In addition, the need for patient education about commonly prescribed analgesics is indicated by this research. Education is also needed regarding the roles, responsibilities and types of support which can, or should, be offered by rheumatologists and/or other health professionals. Patients also require advice about their role in clinical interactions leading to effective pain assessment i.e. to thoroughly present their concerns, fears and problems, irrespective of how busy the clinic may appear and without censoring their pain report to match what they *think* the doctor wants to hear. All of this having been done, further research would then be required to investigate whether increased support and information about pain reporting, the nature of pain and coping with pain would ultimately influence patients' understanding of pain, pain experiences, suffering and the influence of these on the quality of life.

Patients learn implicitly from the doctor through consultations (Berg, 1992). The strong influence of the health professional and in particular the rheumatologist in shaping patients' expectations of RA pain management and clinical interactions about pain is emphasised in these findings and should not be underestimated. How patients and rheumatologists might interact in consultations, what might be said and not said cannot be deduced or extrapolated from these study findings; however, the patient view of what is, and is not, important appears to be strongly influenced by their perception of the experts' actions at the clinic. Health professionals should give thought to what, and how, their action/inaction may label some factors as being important or unimportant at consultation e.g. the relative lack of information given about analgesics.

Health professionals should be encouraged to understand the unique and personal nature of the significance of pain to the individual with RA and of the resultant consequences for the patient's life. This type of understanding may be gained through careful exploration of individual's stories, integrating these with consideration of the patient's age, their role expectations and the stage of the illness. The findings suggest that patients censor their pain reports, or even omit them altogether, underlying the importance of initiating, encouraging and validating the personal pain account. Patients' unique ways of understanding pain assessment and treatment may also

require exploration as these appear to diverge from the medical view. Those who are young as well as those who perceive there is diminishing medical control over their disease may be particularly vulnerable to suffering, as might also those experiencing a 'flare'. Further work is needed to extend understanding of the pain-related support required by those who are young at the time of diagnosis, those who present with therapy-resistant RA and for those patients who are in the later stages of the illness and perceive that medical treatments are failing.

## 10 CHAPTER TEN - FINDINGS AND DISCUSSION -

### RHEUMATOLOGISTS' THEMES

#### 10.1 AN OVERVIEW OF RHEUMATOLOGISTS' THEMES

The key themes presented in this chapter are listed in Tables 10.1a, 10.1b and 10.1c. In these tables, each key theme has an assigned number and descriptive theme label. Several sub-themes (which support the key themes) are also presented, these have been selected as they are considered to be the principal sub-themes that support the key themes (for the full listing of the sub-themes see Appendix 12.1). Within each table 'core themes' are listed (in the final column) these represent the central issues that are proposed to underpin the key themes, these core themes are inter-related to and link key themes and are discussed at the end of the chapter.

**Table 10.1a Rheumatologists' Shared Meanings of Pain – listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
1R	Pain as an expected characteristic symptom of varied patho-biologic origin	<ul style="list-style-type: none"> <li>• Pain as diagnostic in RA</li> <li>• Associating pain with clinical, disease signs</li> <li>• Expectation of long lasting pain in RA</li> <li>• Control pain through slowing disease (no expectation of cure nor complete control)</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attributions of pain to bio-physiological processes</li> </ul>
2R	Pain as a complex, multi-modulated experience	<ul style="list-style-type: none"> <li>• Hierarchy of pain modulators/shapers (with disease as primary)</li> <li>• Non-correlation of disease factors with pain response</li> <li>• Pain influenced by personal factors (age, stage of illness)</li> <li>• Non-consensus regarding non-biomedical pain 'theories'</li> </ul>	<ul style="list-style-type: none"> <li>• The inherent complexity of the pain phenomenon</li> <li>• Compromise in clinical pain management – 'ideals' versus 'real-world' practice</li> </ul>

**Table 10.1b Rheumatologists' Perspectives on the Consequences of Pain – listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
3R	Pain as a negative, disruptive experience in life for those with RA	<ul style="list-style-type: none"> <li>• Pain disables</li> <li>• Pain erodes relationships</li> <li>• Loss of image of present and future self (dependent upon biography)</li> <li>• Suffering with pain</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attributions of pain to bio-physiological processes</li> <li>• The inherent complexity of the pain phenomenon</li> <li>• Compromise in clinical pain management - ideals versus 'real-world' practice</li> </ul>



**Table 10.1c Rheumatologists' Perspectives on Clinical-Contextual Meanings of Pain – listing of key themes, sub-themes and core themes**

Theme No.	Theme Label	Sub-Themes	Core Themes
4R	Difficulty deciphering patients' pain experiences at the clinic	<ul style="list-style-type: none"> <li>• The art of clinical questioning about pain</li> <li>• Patients concealing pain from the doctor</li> <li>• Importance of clinical tests/measures</li> <li>• Priority of disease monitoring over pain</li> <li>• Multiple tasks compete for limited time</li> </ul>	<ul style="list-style-type: none"> <li>• Causal attributions of pain to bio-physiological processes</li> <li>• The inherent complexity of the pain phenomenon</li> <li>• Compromise in clinical pain management - ideals versus 'real-world' practice</li> </ul>
5R	Classifying the pain response in RA: copers, non-coper and denier	<p>'Typing' the patient response to pain based upon an evaluation of the contribution of organic factors to the patients' pain presentation</p> <ul style="list-style-type: none"> <li>• 'copers' (signs of disease are evident)</li> <li>• 'non-copers' (signs of disease are relatively non-evident)</li> <li>• 'deniers' (signs of disease are evident but patient does not pursue treatment)</li> </ul>	
6R	Striving in multiple ways to support the patient with pain	<ul style="list-style-type: none"> <li>• 'Ideals' - to enhance patient's quality of life</li> <li>• Co-ordinator of other health professionals input to care</li> <li>• Shaping custom made treatment plans (individualised care)</li> <li>• Barriers to optimal management or care (time, resources)</li> </ul>	

## 10.2 RHEUMATOLOGIST SAMPLE CHARACTERISTICS

Sixteen consultant rheumatologists were recruited to the study and the stratified sampling quota was fulfilled (see Section 8.3.8). Four females and 12 males were recruited. The mean age of the sample group was 45.9 years (SD 8.9), age range 36-64 years. The mean number of years specialising in rheumatology was 17.1 years (SD 8.4, Range 6-34 years) and the mean number of years since qualification in medicine was 21.6 (SD 9.3). Table 10.2.1 outlines the sample characteristics.

**Table 10.2.1 Rheumatologist Sample Characteristics**

Code	Name (pseudonym)	Age (yr.)	Sex	Years in rheumatology	Type of hospital
D1	Dr Carter	38	M	12	Regional
D2	Dr Elis	37	F	8	District
D3	Dr Adams	43	F	11	District
D4	Dr Silvers	55	M	31	Regional
D5	Dr Bryson	49	M	20	Regional
D6	Dr Brown	36	F	6	District
D7	Dr Howard	64	M	34	Regional
D8	Dr Walls	45	M	10	Regional
D9	Dr Thomas	52	F	25	Regional
D10	Dr Dans	53	M	20	Regional
D11	Dr Barbour	37	M	14	Regional
D12	Dr Mullins	37	M	10	Regional
D13	Dr Parker	36	M	10	District
D14	Dr Gaston	43	M	16	Regional
D15	Dr Whitehall	54	M	22	District
D16	Dr Jones	56	M	24	Regional

### **10.3 RHEUMATOLOGIST RECRUITMENT**

Rheumatologists were recruited from seven different regions of Scotland and from eight different hospital sites.

### **10.4 RHEUMATOLOGIST INTERVIEWS**

Interviews were conducted in private at the rheumatologists' place of work, the mean interview duration being 44 minutes, ranging from 34-59 minutes (the total interview time recorded was 11 hours and 57 minutes).

### **10.5 RHEUMATOLOGISTS' SHARED MEANINGS OF PAIN IN RA**

Rheumatologists' shared meanings of pain relate to their understanding of the connotations of pain in rheumatoid arthritis. Two key themes were generated, both reflective of a pathobiological approach to pain, intertwined with a variety of psychosocial theories:

Theme 1R - Pain as an expected characteristic symptom of varied patho-biologic origin; and

Theme 2R - Pain as a complex, multi-modulated experience.

## **10.5.1 Theme 1R: Pain as an Expected Characteristic Symptom of Varied Patho-Biologic Origin**

This theme relates to rheumatologists' understanding of pain in RA, founded upon their belief in several causal, disease-based explanations supported by their scientific knowledge of RA. This type of account was evident in all interviews. Pain was perceived as a sensory experience primarily related to the body's response to pathophysiological disease processes and longer term pathoanatomical consequences. Therefore, a patient's pain experience is considered to be relative to disease activity i.e. inflammatory responses, or the extent of articular damage arising therefrom. These pain generating mechanisms were seen to commonly present in tandem in RA; the nature of the patient's pain report, along with clinical signs/testing, being used diagnostically to identify the nature of the dominant causal mechanisms. In essence, the pain account paralleled the phenomenon of the activation of nociceptive fibres in and around synovial joints implicated as the sites of disease activity.

Pain.. that is the thing that most people want dealt with. Em and it can vary from pain due to inflammation, where the joints feel swollen and tense and people describe the kind of dull sensation of discomfort all the time, which may well get a bit better as the day goes on. It can also be, in acute exacerbation, when the joint gets very swollen, a sharp pain. But later on the disease when there is joint damage and the joint surfaces are irregular and especially for weight bearing joints, like the knees ankles and hips, the pain may be as a result of the irregular joint surfaces moving together. This pain is often one that catches them on certain movements or goes away with rest but comes on when they start walking or moving about and using the joint. So different types of pain .. and some people will get a mixture of all of them .. you get things going on together. [D14 Dr Gaston]

### **10.5.1.1 The nature of pain in RA**

Rheumatoid arthritis, the disease, was identified by medical professionals as being a characteristically painful condition in which pain presented in recognisable patterns i.e. the nature of pain reports were associated with its diagnosis. It was anticipated that pain in RA would present in the hands, wrists, feet etc, that pain sites could be multiple and variable and that pain intensity could be moderate to severe. When pain was reported to be more intense and increasingly diffuse this was seen to be representative of an acute and, at times, a relatively uncontrolled episode or flare of disease activity. The knowledge that RA is not yet curable or completely controllable was associated with an expectation that complete disease remission was not an achievable goal for the majority of patients. Therefore, the expectation of rheumatologists was that many patients would continue to experience pain, to some degree, throughout their illness. The degree or extent of such pain was unknown and related to the uncertainty of disease progression.

So I think the unremitting nature of the pain em, the possibility of getting complete resolution goes down, you are looking for improvement, rather than making it go away completely. But as well as that, on top of the background level of pain people are getting significant sort of flare ups now and then, which if very frequent can be particularly troublesome. [D13 Dr Parker]

#### **10.5.1.2 Targeting disease processes to control pain**

Pain was identified by nine rheumatologists as being one of the most important consequences of RA and therefore a focus for treatment. Three doctors ranked pain as a primary concern along with disability and loss of independence. Of the four remaining D11 assumed a global view of RA, asserting that the threat to mortality from the illness was his primary focus. The other three (D5, D8 and D12) regarded disability as the primary concern in RA. Their argument was that once an initial degree of pain control was established the pain experience was a lesser issue than disability or fear of disability; since disability is affected by wider factors e.g. the individual's resources. Notably, rheumatologists (D5, D8 and D12) were working in one of the most deprived areas of Scotland. These three doctors considered socio-economic deprivation to be a significant factor in shaping the problems of the patients they cared for. From this group Dr Walls (D8) presented the most articulate and bold explanation, plainly outlining his focus upon the management of the disease and the organic basis of pain, rather than focussing upon the treatment of pain and its consequences.

our focus is mainly on management of the disease process rather than pain itself, with the view that if you actually influence the disease process then you reduce the pain, rather than focussing on the management of pain. ..Firstly, largely because the nature of the pain being chronic and because it is associated with function and disability, a large number of patients with rheumatoid focus on their function and disability rather than the pain. I think the general way of approaching a consultation is by asking the individual about the problems they may have been having... recognising in my own practice that pain is not what they bring up as their main problem, it is disability. You know, that is what my understanding is of rheumatoid arthritis, that disability is their big problem, or that their fear of disability is their problem. [D8 Dr Walls]

Dr Walls' primary orientation to pain was to treat the biological 'cause' of the pain in a medical way. Although other respondents identified that pain itself (as a multi-dimensional phenomenon) was an important target for treatment, similarly, their primary focus was upon controlling disease activity. In accordance with the importance levelled at the pain experience in RA and its basis in disease or nociceptive mechanisms, rheumatologists identified that pain control through disease modification was a key goal of interventions. Although Dr Walls' account of attending to the biological causes of pain was more directly articulated than others, his statement is a

reflection of the strong sub-theme of pain control being mediated primarily via disease oriented treatment (i.e. using disease modifying drugs). Dr Whitehall, for instance, clearly indicated that his management was based firmly upon control of disease rather than consideration of wider pain issues or through considering pain as an issue in its own right.

you have a role in terms of identifying where the pain is arising from, and what you are doing for the pain and trying to identify the cause of the pain. I am largely trying to look and see what I can do, to try and reduce the nature of the problem that is causing the pain, so that you try to determine whether it is inflammatory in nature, degenerative in nature and then try to change the disease process itself rather than saying 'I am going to deal with pain, as the end product'. [D15 Dr Whitehall]

Only one rheumatologist mentioned the importance of treating nociceptive pain quickly and effectively in relation to the detrimental effects that untreated pain itself has upon up-regulating the sensitivity of the body, thus risking augmentation of chronic pain mechanisms (Jensen et al, 2001). He advocated using analgesics and disease control measures quickly and aggressively to suppress pain. This approach is a reflection of an understanding that pain is wider than simply disease based. It was initially assumed that this doctor (D13) may have had a different background or training than had his peers but, when further questioned, this appeared not to be the case.

#### **10.5.1.3 Theme summary**

This dominant theme (Theme 1R) directly associates the pain experience in RA with scientific knowledge and understanding of pathological disease processes. The associated accounts represent a causal, reductionist, disease-based model of pain. Correspondingly, patients' pain reports, along with clinical signs/measures, are valued as being diagnostic and relative to organic events within the diseased body. Pain control is mediated by treatment aimed at slowing disease activity although, it is generally anticipated, this will not be fully effective due to the limitations of currently available interventions. Expectations are that the patient will experience some degree of pain throughout their illness.

#### **10.5.2 Theme 2R: Pain as a Complex, Multi-Modulated Experience**

Disease processes and the biological consequences of these were viewed by rheumatologists as being the fundamental cause of the pain experience in RA; however, a range of diverse factors were offered as potential modifiers of the pain experience in RA and are the substance of this theme. Based on the assumption that there is

an organic basis for pain in RA, hierarchies of pain modulating influences were suggested. In this way, pain was conceived as a phenomenon shaped by more than just the medications used to slow disease and included psychological, social and contextual factors.

..well it [pain] will fluctuate with disease activity.. when the rheumatoid arthritis is going through an active phase then the stiffness and pain will tend to be worse in a number of joints.. The pain which is due to, not just to inflammation but to joint damage, eh which leads to secondary osteoarthritis, so there may be a focus of pain in a particular joint, .. there are different kinds of pain, the type associated with active inflammation and the pain associated with pre-existing joint damage, which leads on to osteoarthritis. But having said that pain is also affected by a whole number of other variables depending upon a patient's social circumstances, their coping strategies, their psychological status, you know all these other factors which have a major aspect in influencing pain. [D4 Dr Silvers]

The pain experience was still conceived as a signal of nociceptive activity but one which could be augmented by beliefs or mood, at the same time noting that the pain report did not always parallel the disease indicators. The pain experience was anticipated to be shaped by the patients' interpretive framework, context and time i.e. the pain experience was conceived as a more complex phenomenon, influenced simultaneously by a number of factors. [The most commonly presented factors modulating pain are outlined in Table 10.5.2.] 'Non-biological' factors presented most frequently were depression and anxiety, commonly associated with the early stages of the illness. This phase of illness was considered particularly pain-filled as the disease was uncontrolled and pain was augmented by anxiety, fear and/or depression related to the news of their diagnosis and/or to anticipation of the diagnosis and its consequences.

**Table 10.5.2 Factors Offered by Rheumatologists that could influence Patients' Pain in RA (n = 16)**

Influencing Factor	No. of Rheumatologists mentioning this factor (%)
Disease related, nociceptive factors	16 (100%)
Medical interventions to slow disease activity	16 (100%)
Psychological ill health e.g. depression, anxiety	16 (100%)
Beliefs, knowledge, attitudes	16 (100%)
Activity levels i.e. movement	12 (75%)
Social support available	12 (75%)
Sleep deprivation	8 (50%)
Learned responses	6 (38%)
Socio-economic status	6 (38%)

Bio-physical factors re-emerged as important considerations in shaping pain, this reflected the emphasis placed on nociceptive processes in Theme 1R, for instance, activity levels and inter-current illnesses; this latter was mentioned by 50% of respondents and is a probable reflection of their experience in dealing with significant co-morbidity in RA. Interestingly, patient deprivation or socio-economic status was only mentioned by those rheumatologists working within the most deprived areas of Scotland and not by any of those in more affluent areas. This suggests that experiences with particular patient groups may focus attention upon particular pain issues.

there are so many factors [that influence the pain experience], one is family support, one is personal resources of how they deal with things, the other is how well they can be distracted. If they can stay at work it is amazing how pain recedes that bit or if they have some other focus, em. There is no doubt that if patients have co-morbidity or other diseases which makes it harder for them to cope, its layer upon layer, and family disturbance such as bereavement or children moving away has a profound effect on how patients perceive the pain and cope. [D9 Dr Thomas]

Rheumatologists' accounts were characterised by a seemingly random and diverse presentation of non-disease factors that could influence pain i.e. there was no apparent systematic way of organising their views about pain. There were a variety of ideas and theories from the biomedical realm, psychology (e.g. locus of control, social learning theory) with some associated with the integration of social and cultural theories (the latter limited to two accounts). The biopsychosocial model for understanding pain was not used as a basis for any explanations. 'Personality' was mentioned by 44% of doctors but, as was noted in the research diary – "at interview there was not enough time to explore doctors' conceptions of what they meant by 'personality' as it appeared they were alluding to different things e.g. traits, ability to cope etc". Other factors which were mentioned less commonly included educational achievement, gender and genetic predisposition. Overall, there was a hesitancy and degree of uncertainty about their having been comprehensive in their accounts, a phenomenon not evident in their biomedical explanation of pain. Dr Parker talks about factors that shape the patients' pain experience:

Whether there is also a psychological thing as well, where people who believe that they can control their pain, or have some influence on their pain are more likely to respond to treatment rather than those who see it as something that has to be done externally by going to see somebody, so their locus of control is away from them, its for someone else, they tend to deal with pain differently. Other things that influence the pain.. I suppose their own personal experience of pain, whether there is someone else in the family or there is sort of a cultural.. influence. em, on how people deal with pain. [D13 Dr Parker]



Understanding something of the complexity and diversity of the factors shaping the pain experience in RA was related to explanations of the difficulty encountered in clinical pain assessment (described in Theme 4R).

### **10.5.2.1 Theme summary**

The complexity of the pain phenomenon in RA is broadened from its assumed, proportional relationship with disease processes to incorporate a diverse range of personal, psychological, social and cultural influences. The biological or mechanical influences are dominant sub-themes shaping pain e.g. medication, activity levels. The most prevalent non-biological factors offered were psychological health and cognitive factors i.e. beliefs and understanding. This appeared to be related to doctors' experiences of patient presentation. Rheumatologists' accounts were characterised by a lack of consensus within the group about the range of factors which could affect pain in RA. This included biomedical theories related to disease and personal factors, such as patient knowledge of RA, plus evidence of a collection of piecemeal psychological and social theories. These were not as fully or clearly described and developed as were the biomedical explanations of pain.

### **10.5.3 Discussion of Rheumatologists' Shared Meanings of Pain**

Study of rheumatologists' conceptions of pain is novel, consequently, there is no directly comparative literature available. However, in the absence of previous research, the findings from studies investigating other health professionals' pain beliefs plus evaluation of the characteristics of rheumatological text discourses about pain assessment and treatment were seen to serve as a relevant basis for the discussion of the findings. The dominant explanation of pain in Theme 1R parallels doctors' understanding of pain in RA with the pathological medical model that has been evident since the end of the 18<sup>th</sup> century (Armstrong, 1995). Rheumatologists' saw pain in RA to be a symptom of the disease, which could be corroborated through expert clinical assessment of bodily signs e.g. swelling, typical of the active inflammatory disease processes characteristic of RA. Although pain theory has advanced from simplistic specificity theory to models of multiple, interactive processes and systems (Kugelman, 1997) the reductionist, nociceptive foundation of pain in RA dominates rheumatologists' account of pain in RA. This corroborates the observation of others that doctors continue to emphasise linking pain to a cause located within the body (Sullivan, 2001, Priel et al, 1991). This also concurs with an emphasis upon biological, disease processes found in the rheumatological literature. This focuses upon the use of pharmacological methods to slow disease processes as the accepted route to improving long-term functional outcomes (Kwoh et al, 2002;



Fries, 2000). Pain control, in itself, is seen as being only one target among a multiplicity of treatment goals (Scott et al, 1998; SIGN, 2000).

Educational background and training shapes doctors' orientation to pain (Eccleston et al, 1997; Rainville et al, 1995) and it is suggested that medical training remains grounded in biomedical models of care (Ramos-Remus et al, 2000) insufficient attention being paid to pain management and pain assessment (Rich, 2003). Although rheumatological texts generally espouse an eclectic, biopsychosocial approach to rheumatological care (Simon et al, 2002), RA is clearly identified as a condition which manifests a relatively direct and proportional relationship between pain report and biophysical factors (Dessein et al, 2000; Rice and Pisetsky, 1999). This is reflected in these findings where, paralleling the disease-orientated explanation of pain in RA, a disease-focused approach to assessing and managing pain is presented, albeit at times shrouded in a statement that pain itself is a focal issue for treatment, in its own right.

Pain in RA has a diagnostic function in early presentation of the condition and also at times when pain is classified as acute, however, studies suggest that, like other chronically painful conditions, pain is only moderately related to disease in RA (Coster and Bengtsson, 2001; Smedstad et al, 1995; van Lankveld et al, 1993). Psychosocial factors are well established moderators of the pain experience in RA (Brown et al, 2002; Manne and Zautra, 1989; Sharpe et al, 2001; Smarr et al, 1997; Young et al, 2000). Over emphasis of the biological foundation of pain in RA risks obscuring factors which should be considered to enable effective pain support provision. Although disease processes were at the heart of pain explanations, rheumatologists were cognisant of the non-disease factors shaping pain and these formed the basis of the second theme (Theme 2R)

Accepting that biological attributions of pain in RA were the dominant pain explanations, discussion of the wider, non-physical or non-mechanical influences that shape pain generated a range of ideas about psychological and social factors. This conception of pain mirrors Vrancken's (1989) definition of a 'Dualistic, Body-Orientated' theme which was developed from the accounts of Dutch pain specialists. These accounts were typified by their reference to physiological pathology as a prerequisite for pain, with contributing social and psychological factors influencing the experience. Vrancken's (1989) 'dualistic' descriptor, related to doctors' accounts of clinical practice where treatment was orientated around evaluation of the relative contribution of 'component parts' i.e. 'mind' factors versus 'body' factors. This compartmentalisation of body versus mind pain modulators was also

found in rheumatologists' accounts of how they evaluate patients' responses to pain in RA. This subject is dealt with in Theme 5R (Classifying the Pain Response in RA) where its implications are also discussed.

Unlike biomedical explanations for pain, which integrated biological theories and explanations regarding pain mechanisms, there was no apparent framework for arranging knowledge of psychological, social and cultural influences. By contrast, in Eccleston et al's (1997) study of pain professionals' understanding of the causes of non-defined chronic pain, experts presented coherent accounts, linking pain with theories of maladaptive learning and loss of control. Those with a psychological background or having a specialist interest in chronic pain management are potentially more likely to draw upon other, non-biomedical models of pain e.g. illness behaviour models (Hanson and Gerber, 1990, p22) or biopsychosocial models (Keefe and Bonk, 1999). Despite the biopsychosocial model of pain being promoted as a means to understand the influences, consequences and approach to pain management in RA (Simon et al, 2002; Keefe and Bonk, 1999), it was notable by its absence in rheumatologists' accounts. The lack of structure or organisation of non-biomedical pain theory was not alluded to within the literature and may not have been apparent in studies using questionnaire or survey methods which give pre-structured responses (e.g. Green et al, 2002; Rainville et al, 2000). In contrast, this study invited the consultants to present a narrative related to their understanding of pain. The lack of any apparent guiding framework for pain talk, outside the biomedical discourse, may be related to the doctors medical background and/or training which primarily frames illness in terms of disease, biomedical dysfunction and biomedical solutions (Kleinman, 1988; Toombs, 1992). The disease-focus in rheumatology is, I would argue, not conducive to fostering an interest in and specialist knowledge of, chronic pain systems and management and this is perhaps reflected in the paucity of rheumatologists who are members of pain interest groups (IASP Directory of Members, 2003-2004). The problem thus posed is that, without a framework designed to increase and support the rheumatologists understanding of chronic pain, these specialists will continue to lack the ability to assess the complex influence on and/or consequences of chronic pain. These points are reflected in the Clinical-Contextual Themes 4R, 5R and 6R that address issues of clinical pain assessment and management in RA.

## 10.6 CONSEQUENCES OF PAIN IN RA - RHEUMATOLOGISTS' VIEWS

### 10.6.1 Theme 3R: Pain as a Negative, Disruptive Experience in Life for those with RA

This theme relates to rheumatologists' accounts covering aspects of the impact on the life of patients living with chronic pain associated with RA. These accounts emphasise the broadly detrimental, but at the same time, unique personal nature of the impact of pain. The effects of pain were conceived as being dependent upon an individual's age, roles, responsibilities and circumstances, the impact extending beyond the unpleasantness of the experience and imposing limitations upon the body and 'self' whilst interfering with family relations and wider social roles. Doctor Gaston responded to the question about how pain impacted upon the lives of patients he saw:

Pain..., struggling, an effort for normal activities of living to be performed, being prevented from what you would expect to perform, employment, normal every day things: getting down stairs, driving and taking what we do for granted and having that taken away from you. Flare-ups, with very severe pain and very severe swelling, side effects of drugs, feeling rotten most of the time, knowing that the drugs that you are taking are probably harming you and having to take that risk. Having to consider surgery and the risks that that entails and knowing that surgery doesn't last forever, knowing that you are committing yourself to long term therapy. I guess that is probably the worst of it. [D14 Dr Gaston]

This account was unusual in its reference to the negative impact of medical treatments as only two other rheumatologists raised this point. In contrast, the accounts of the impact upon individuals' function, or issues of disability were common (see Table 10.6). Questions about pain impact generated extended responses, free-flowing narratives of patient examples, more lengthy and easily elicited than talk about the factors that influenced the pain experience. These accounts reflected the wealth of experience the rheumatologists had in listening and attending to patients' accounts of how RA and pain was affecting them and was evident in the frequent use of case illustrations to illuminate the narratives.

**Table 10.6 Consequences of Living with Chronic Pain in Rheumatoid Arthritis (quantified from rheumatologists' accounts)**

Nature of the Consequences	Number of Rheumatologist Presenting the Particular 'Consequence' in their Account (%)
Functional limitation or disability	16 (100%)
Interference with valued social roles e.g. in relationships	12 (75%)
Negative affect upon mood or psychological health e.g. depression	12 (75%)
Economic hardship (through loss of work)	8 (50%)
Loss of image of future and future self	5 (31%)

The nature of the consequences of chronic pain were seen to be closely related to the age of the individual affected and their roles or responsibilities in life at the time of diagnosis. Dr Adams' account (Figure 10.6) is selected as it covers a range of issues in one section of text i.e. impact upon new mothers, elderly persons etc. and inter-relates the limitations imposed with practical, personal, social roles and expectations.

**Figure 10.6 A Quotation that Typifies Rheumatologists' Understanding of the Unique Nature of the Consequences of Pain in RA**

.. pain, first of all.. the effects depend upon what age group they are in. Many of our patients are relatively young people; well some of our patients are very young. so.. if it was a working age person it is their immediate loss of independence, their ability to work and be the breadwinner and bring money into the family, if they have a family. But it is the loss of independence because of the symptoms, they should be young fit and active and they can't do any of these things again, any more. And along with that there is the loss of self-esteem and social status and em, depression. If it was another category, which is really difficult, that is the mother, postpartum onset of inflammatory arthritis and all the difficulties, which come along with it. Having to care for your child or however old it is... But that is incredibly difficult trying to support them [the mother]. There are all sorts of different kinds of thoughts that apply to them; their guilt at not being a good mother, and caring, as well as the pain and the physical difficulties of changing nappies. And then of course there is the older person who maybe isn't working any more but maybe who looked forward to their retirement and doing all sorts of things and they can't do that. Or they are caring for a spouse and they were the strong one. Or else just the misery of.. sort of, you know, in your older years, just being governed by pain and limitation and physical difficulties. [D3 Dr Adams]

People developing RA at a relatively young age, with dependent family members, were consistently identified as a group of patients particularly susceptible to profound negative, disruptive experiences when pain limited their capacity to work and support others in a way they would expect for their age and circumstance. Equally, the consequences of pain were noted to be significant in the early stages of illness when the patient may be filled with fear and uncertainty about their future and lack knowledge and experience of pain control, all of this augmenting the pain experience. The emergence of this focal topic in the rheumatologists' accounts may be a reflection of the prominence of the patients' distress and concern conveyed to rheumatologists when attending first consultations in contrast to those attending with established disease.

The variability of the impact of pain for each individual was emphasised in accounts and was linked with the factors shaping pain identified in Theme 2R e.g. those with greater social support being able to accommodate/adapt more successfully. Fear, related to pain, was only mentioned by two respondents (D2 and D3) both related to pain experiences in an acute flare situation or on initial presentation at the clinic. Most emphasis was upon the long-standing, day-to-day consequences of pain, rather than on episodic acute flares. This might reflect the nature of the interview questions. The provision of pre-interview contextual information guided rheumatologists towards talk about patients with established RA and who would be reviewed at least yearly at clinics (not emergency cases fitted into clinics).

‘Suffering’ was not quantified within the tabulated findings (see Table 10.6) as rheumatologists did not distinctly identify pain with ‘suffering’. However, dimensions of suffering were repeatedly offered in accounts, through talk about the loss of valued roles and eroded images of self via loss of function allied to the loss of vision of a valued future. All of the rheumatologists acknowledged that the impact of pain was always greater than the impairment inflicted upon the body by pain. The relative success of adaptation to life with pain, or otherwise, was also integrated within accounts, as was appreciation that some ‘types’ of patients and sets of circumstances were more conducive to minimising the disruptive impact of pain than others (this is developed in Theme 5R).

There is a huge impact on the family.. it is not an individual's disease, if they are in a family then it is going to spill over into both the ways in which the family dynamics work too, whether it is a male, is he able to do the 'normal' male things? Or if it is a lady, a wife, then domestic problems and re-balancing it.. There is that aspect of it but also the relationships within the family, husband-wife, the relationship dynamic can change quite dramatically because I think with things like tiredness and pain, all kinds of practical things. I think there is still a potential gap of understanding [between patient and their partner], because tiredness is a very relative symptom and pain is too, and I think it is very difficult to understand what other people mean sometimes, and that can create friction in a relationship. And as I say, some people are really great and you see heroic acceptance of changed circumstances, from spouses or partners. It is amazing the level of sacrificial service that comes into a marriage sometimes because one person develops rheumatoid arthritis. [D10 Dr Dans]

### 10.6.2 Summary and Discussion - Theme 3R

This account of pain clearly demonstrates rheumatologists' cognisance of the widespread consequences of pain, not focussed narrowly upon the biological or physical consequences e.g. limitation, but extends to integrate the impact upon individuals' sense of self, their family and interactions within the wider social world. Thus, the

impact of pain is seen to be dependent upon personal and biographical details, the stage of life at which pain onsets, the expectations for life, family relations, economic circumstances etc.

As previously mentioned, exploration of rheumatologists' perception of the consequences of pain for patients is a novel area for study. The only similar study found was Paulson et al's (1999) exploration of the narratives of four Swedish doctors' regarding men's experiences of living with non-defined chronic pain. Paulson et al (1999) reported that doctors identified pain as potentially threatening an individual's self-identity, along with other issues more closely related to the contested nature of the diagnosis. The findings from the present study show doctors presented interwoven accounts of the negative impact of pain in relation to the patients' body, self, family and others. The recall of actual cases and the evaluation of the impact of pain was presented as a way to organise the 'consequence' account. This produced rounded and comprehensive reports that paralleled patients' accounts of the impact of RA and pain (Bath et al, 1999; Locker, 1983; Newman et al, 1996). This augers well for the ideals of patient-centred care, where the doctor is required to show understanding of the patients' illness experience and personal illness meanings (Mead and Bower, 2000). This suggests that doctors could fulfil patients' wishes to be accompanied throughout the process of their unfolding illness with understanding and empathy (Arthur and Clifford, 2004; Charon, 2001) and especially to be treated as an individual with specific personal aspirations and a unique illness experience (Quest et al, 2003).

Rheumatologists' emphasised the distress and difficulty of coping with pain in the early stages of illness and this reflects patients' reports of the importance of having pain attended to at first clinic presentation (Hughes et al, 2002). However, there were few references to how the elderly or those in later stages of the illness experience pain. There is no categorical evidence to suggest that pain experiences diminish with time (see Section 3.2.5.1), indeed there is suggestion that pain reports may increase with age (Jakobsson and Hallberg, 2002). The focus upon the magnified pain experience in initial stages was related to the patients' lack of knowledge and understanding about pain and RA. However, it is notable that irrespective of the duration of illness, patients with RA tend to lack knowledge about the disease and illness (Barlow et al, 1999; Hill et al, 1999) and request such information at all stages (Arthur and Clifford, 2004; Barlow et al, 1999; Kay and Punchak, 1988). Treatments and medical regimes can be viewed as a burden by patients with RA e.g. living with the side effects of treatment (Bath et al, 1999; Goodacre and Goodacre, 2004; Katz, 1998; Mahat, 1997). However, this was not a feature in rheumatologists' accounts. This may reflect doctors' perception of the necessity of medical interventions to

improve long-term outcomes but could also be a consequence of the limited number of topics which could be covered during the interviews for this study.

Overall, the focus of the rheumatologists upon the personal, disruptive consequences of pain for the individual was more closely aligned with how patients' describe the impact of RA than might have been expected, after the biomedically-biased framing of pain discussed in Themes 1R and 2R. The literature provides numerous examples of how medical and lay views of illness and pain are discordant (Honkasalo, 2000; Jackson, 1994; Toombs, 1993). This study's findings support a concordance of views in relation to the consequences of pain which would support a patient-centred approach to care, where the foundation of effective communication and the involvement of the patient in care is brought about through the expert knowing something of the patients' illness experience (Mead and Bower, 2000).

## **10.7 CLINICAL-CONTEXTUAL MEANINGS OF PAIN IN RA - RHEUMATOLOGISTS' VIEWS**

Clinical-contextual meanings of pain relate to clinical pain issues e.g. pain assessment, pain reporting at a consultation etc. Three themes were generated from the rheumatologists' accounts:

Theme 4R - Difficulty deciphering patients' pain experiences at the clinic;

Theme 5R - Classifying the pain response in RA: copier, non-copier and denier;

Theme 6R – Striving in multiple ways to support the patient with pain.

### **10.7.1 Theme 4R: Difficulty Deciphering Patients' Pain Experiences at the Clinic**

This theme relates to rheumatologists' perception of the difficulty and complexity of attempts to fathom the nature of patients' pain experiences in the clinical setting. The theme is constructed from talk of the techniques used clinically to make sense of the pain i.e. using questioning and objective measures to enable alignment of interventions with a planned course of action. In essence, the rheumatologists aim to evaluate or 'sort out' the relative 'weight' of a number of inter-related factors understood to be contributing to the patient's pain experience and report. These factors include biophysical causes of pain (Theme 1R) and/or modulators of pain (e.g. mood, Theme 2R) along with a mixture of social-interactive factors which might influence the pain report,



such as concealing the pain report from the doctor. This latter point, is the first clear distinction in rheumatologists' accounts made between pain as a sensory experience and pain as a behaviour i.e. pain being a phenomenon dependent upon the nature of the pain presentation by the patient. In essence, pain in RA is viewed as a difficult phenomenon to assess, as there are no available objective measures. Combining this with the limitations of time and resources, the work of clinical pain assessment is viewed as challenging and at times frustratingly inadequate.

### **10.7.1.1 The art of questioning about pain**

When asked about how they actually assessed patients' pain at the clinic all rheumatologists reported the main method was through the judicious use of a range of questions (Table 10.7.1 outlines the most commonly presented techniques for assessing pain clinically).

**Table 10.7.1 Techniques Reported by the Rheumatologists Used to Assess Patients' Pain at the Clinic**

Methods used gather information about the patient's pain experience	No. of rheumatologists (%)
Asking a range of specific, personal questions	16 (100%)
Physical examination and observation of movements and joints	15 (94%)
Process measures (e.g. ESR or CPR)	12 (75%)
X-rays or imaging	7 (44%)
Use of self report questionnaires (e.g. HAQ, occasional)	4 (25%)
Use of visual or verbal pain scale (occasional)	4 (25%)
Use of pain diary (occasional)	1 (6%)

Information about patients' pain experience and the consequences of pain were sought through clinical questioning which encouraged the patient to focus upon issues related to daily function or quality of life, rather than generate a focus upon the body and pain as a sensation. Open-ended, conversational-type questions were favoured over pain-specific questions, so countering the tendency for some patients to deny they had problems and also to allow an overview of the general nature of their problems. This broad outlook was used as a starting

point to decipher what range of factors might play a part in a patient's problem/s e.g. social circumstances, disease factors. Patients' responses were subsequently deconstructed to aid working towards an evaluation of the factors which supported the patients' pain presentation and experience. This type of assessment was construed as the 'art of medicine' (D12), and was based upon clinical experience, sometimes guided by intuition, so allowing the clinician to move swiftly towards what is considered the heart of the problem or patient concern, whilst always working within limited consultation times.

I think to a certain extent you have to ask an open question and maybe ask some background questions about what is happening in the family etceteras. So I think there are one or two open questions that you have to have, rather than, 'how are your joints today?' Asking, 'How are you today?' or 'How have things been happening with the family?' And these open questions will sometimes uncover you know, issues which are really troubling the patient. [D4 Dr Silvers]

You often have long-term relationships with these patients, watching them through different phases of life. .. And so, you get to know them well and sensitive questioning..., and its not difficult to pick up, again, with intuitive clinical skills when people are not right.. if you have met them before it is sometimes easier. You know about things from the past, six months ago there was a problem with the marriage, and so you will probably go into that area fairly quickly as part of the overall assessment. [D10 Dr Dans]

#### **10.7.1.2 The importance of disease measures and observations**

In addition to patient questioning, rheumatologists reported balancing the pain report with more objective assessments e.g. observation of the patient's movements, attending to inflammatory markers (e.g. ESR) to evaluate the correlation between what was said and what could be seen or measured. These assessments were considered to provide vital information about the state of the body, inflammatory processes and the pain experience. This reflected the hierarchy of factors presented in Theme 2R i.e. factors influencing the pain experience. In addition, the responsibility of the rheumatologist to attend to the monitoring and assessment of the disease activity and its impact upon the body is fundamental to the work of the medical expert in RA management. Although wider issues related to pain are considered through the assessment processes, this is always under-pinned by consideration of the degree of joint damage and inflammatory activity.

.. I don't regard it as my job to judge [i.e. to judge a person because of the nature of the pain complaint].. when their [patients] pain seems to be primarily a function of the active disease, usually inflammation, and where there is inflammation that is something that I feel I ought to be treating and improving. And obviously there are different types of pain and sometimes it is more of a mechanical pain which may require surgical intervention. And I suppose I see that as my job, is to identify when the pain is due to inflammation which I ought to be treating or mechanical pain which may require a different line of treatment. But equally when people have pain

that doesn't seem to be a consequence of their disease being worse, you see someone and objectively you think, well there isn't much inflammation here, there isn't much damage and they are still in pain. I suppose that's when you have to say, well, 'are there other reasons why you are in pain?' [D11 Dr Barbour]

This quotation represents the majority view among rheumatologists where, ultimately, the biomedical basis or disease activity was used as the benchmark around which other accounts of pain are arranged and assessed. Accounts where patients' pain report was considered an unreliable indicator of disease are typified under the following three headings:

1. When the patient's pain experience does not appear to correspond to the underlying disease which progresses unnoticed by the patient (considered rare);
2. Where non-organic factors e.g. social issues, are considered to be more prevalent than organic factors in shaping the pain report or complaint (the 'non-coper', described in Theme 5R);
3. When the patients may consciously under-play or conceal their pain and consequences of it (the 'copers', described in Theme 5R).

In cases where disease indicators or measures were not paralleled by pain reports or the observed level of disability, non-organic factors such as psychological or social issues were considered key. These cases were thought to present the greatest challenge in terms of pain assessment and were associated with the greatest degree of doctor frustration (expanded in Theme 5R). Dr Jones (D16) describes using a combination of experience and questioning to ascertain the basis of the pain report and distress. Where there is little evidence of active disease, relative to the pain report, there is concern that it may not be possible to determine what is contributing to the pain and distress and thus diminish the ability to offer appropriate support.

I think that depends on the nature of the problem. I think that if we were talking about someone at one end of the spectrum who had a structurally damaged hip, and so who needs a hip replacement, and although the emotional factors play a part, the nociceptive factors are probably more dominant. Move the other end of the spectrum where perhaps there is little or no joint damage, the inflammation not particularly intense, and nociceptive factors are playing a part but for some patients the emotional factors may have quite a big effect in amplifying them and may be the dominant factor. And so it depends on the individual and the context and so forth. But to try and tease these out in individuals is almost impossible most of the time. [D 16 Dr Jones]

Where patients are considered not to say how they actually felt or in some way attempt to conceal their pain and suffering from the doctor at the clinic, a variety of hunches and theories were offered by the rheumatologists (see

Figure 10.7.1). Some ideas overlapped, others were distinct, but all appeared to have a basis in clinical experiences of the rheumatologists.

**Figure 10.7.1 Rheumatologists' Ideas about Why Patients Might Under-Report or Fail to Report Pain at the Clinic (no one explanation was more prevalent than the others)**

- Want to please the doctor by reporting they have got better with the treatment given to them and visa versa don't want to report therapy is not working
- Giving positive feedback to the doctor may result in this being reflected back to them and provide a sense of assurance that things are not deteriorating
- Not wanting to burden the doctor with more problems
- The doctor appears busy and not to have time to hear concerns
- Think there is nothing else that can be done anyway
- Have learned to accept or deny their pain and not complain about it (Theme 5R - 'copers')
- Don't want their medication or treatments altered or want to avoid hospital admission
- Don't want to admit they are getting worse (Theme 5R – in denial)
- Don't want the extent of their suffering known by another

Dr Silver's (D4) account was the only example of critical, self-reflective thought about how the specialists' questions and/or non-verbal communication could impact on the patients' report. This emphasises the lack of reflection by the other professional participants about what processes or factors shape patients beliefs and behaviours i.e. what lies beyond the patient thinking that reporting improvement pleases the doctor?

**I:** How do you judge how well you are managing their pain? **Dr Silvers:** I think that is a very difficult question because I suspect in a consultation in an out-patient clinic in hospital, patients do not tell us all the facts. They want to please the doctor on the whole. **I:** why is that? **Dr Silvers:** I think its because the patient want to have the doctors on their side. And they know that doctors like to hear that they are doing reasonably well. And I suspect patients don't tell us the true nature of things because of that or because they appear, the doctors, that they are being rushed and therefore don't have time to hear it all. And they respond to the doctor's specific questions and don't add in other things. Now there are obviously exceptions to that but I suspect in a fifteen-minute consultation we don't really get to the bottom of many patients' problems. [D4 Dr Silvers]

### **10.7.1.3 Other important assessments taking place during consultation**

In addition to assessment of such things as disease activity, pain experience and its impact, other important medical issues were deemed vital to clinical assessment i.e. general health, drug toxicity. With a time limit of approximately 15 minutes or less for consultation, the potential for compromise and to just focus upon disease factors and other issues that may threaten the patient's overall health and well being is likely. Such compromise was alluded to by approximately one quarter of respondents, talking about the review clinic as 'crisis management' and dealing with the 'biggest problem' only (D2) or it being unlikely that the rheumatologist obtained a true impression of what the patients' problems were (D4, D3 and D8). Dr Gaston provided the most obvious account of this:

..for return visits for rheumatoid, we are prioritising drug toxicity, so I think probably my number one reason for seeing them is to check we are not poisoning them too much. So we would want to check on their general health, check on any blood evaluations that have been performed by their GP usually. Make sure that they are not toxic from their drugs. We also want to determine whether the level of disease burden is less for them than the last visit let's say. So a very simple clinical assessment, with simple clinical questioning is by and large all we have time for [sighs]. [D14 Dr Gaston]

### **10.7.1.4 Non-use of self report questionnaires and measures**

The use of self report questionnaires about pain or function or visual analogue scales for pain were not routinely used in clinical practice. The range of reasons for this varied from not having resources of staff, equipment (e.g. computers or time to use them), additionally some doubted the validity of those currently available (e.g. The Health Assessment Questionnaire, see Appendix 3.4) questioning their value in informing clinical decision making.

## **10.7.2 Summary and Discussion - Theme 4R**

Theme 4R stresses the complexity and difficulty experienced in the clinical work of evaluating the pain experience in RA. Themes 1R, 2R and 3R, already outlined, are inter-related with this theme as the clinician is faced with the solo task of attempting to ascertain the basis of the patient's pain report which is complicated by a multiplicity of factors converging to shape the pain phenomenon. Compounding this complex task, rheumatologists' consider that some patients might conceal concerns or problems which are relevant to the assessment, but there is a lack of consensus among rheumatologists regarding the basis for this. With infrequent

use, or non-use, of self-report measures, pain assessment ultimately depends upon a few select questions, guided by clinical experience, often having to be asked within one short consultation. Patients' responses to clinical questions were counterbalanced or outweighed by doctors' attendance to the findings from clinical tests/measures used to assess the contribution of disease processes and related biological consequences to the pain experience. This confirms a common belief in the fundamental influence of disease on pain (Theme 1R). Rheumatologists' identified their primary role as 'managing the disease' and monitoring related medical threats to patients' health. This, combined with limited time and resources, may result in a compromised pain assessment, directing the doctor to focus specifically on disease assessment. The rheumatologists acknowledge that it is unlikely that the doctor is able to capture the extent of patients' problems and understand the basis of their pain experience with this approach to clinical pain assessment.

The use of questioning as the prime means to assess pain and pain consequences at clinical reviews in RA is supported in the literature (Bellamy et al, 1998 and 1999). Using a limited number of personal and biographical type questions, the doctor is engaged in an interpretive act, in an attempt to gain an inkling of what factors may be contributing to the pain presentation. This is in contrast to the pain-assessment recommendations of the American Pain Society for RA which advocate the use of patient self-report questionnaires and various other pain measures (Simon et al, 2002). The non-use of self-report measures and the relative inattention to pain specific measures in rheumatological clinical practice has been alluded to in rheumatological literature (Bellamy et al, 1999; Flowers, 1998; Wolfe and Pincus, 1999). Reasons presented for this, arising from this study, relate to limited resources of time, staffing and equipment and this is also documented by others as a general issue in clinical care in RA (Guillemin, 2000; Stowers et al, 1999; Wolfe and Pincus, 1999).

In clinical practice the use of carefully selected personal questions may be viewed as the quickest route in attempting to evaluate dimensions of pain which are not evident through clinical testing and observation e.g. emotional or social factors. The use of conversational communication is accepted as a key method in gathering information about patients' value-laden meanings (Kleinman, 1988). However, rheumatologists say that this is a crude method of assessment and one unlikely to allow the clinician to adequately assess and subsequently address multiple pain dimensions, given the limited time available for this at consultations.

The varied nature of the questions used by rheumatologists in attempting to reach the 'heart of the matter' is a reflection of the variety of 'non-disease factors' believed to influence pain in RA (see Theme 2R), leading to a lack of a cohesive or systematic way of thinking about clinical pain assessment. The lack of a theoretical guide for clinical practice is noted in the literature where pain experts fail to show a coherence between their purported model of work (e.g. pain gate theory) and actual practice (Baszanger, 1992). The biopsychosocial model may serve as a theoretical model for pain assessment (Keefe and Bonk, 1999) but rheumatologists made no reference to it in the context of questions about clinical pain assessment. This may reflect the criticism that the model lacks clinical utility, as the doctor incorporates knowledge outwith the scientific realm in clinical work, having to consider social dynamics, what they can do with their given resources and ethical issues (Baszanger, 1992; May et al, 2004; Sadler and Hulgus, 1992). Rheumatologists in this study took into account issues of patient non-communication and concerns about consultation time limits, issues touched upon only briefly in a few studies of patient experiences (Barlow et al, 2002; Donovan, 1991; Ryan et al, 2003b).

Asking rheumatologists to describe and explain how they clinically assessed pain revealed the inherently 'messy' and complex nature of assessment, issues of interactions, censoring of reports, use of intuition, over-speedy interpretations etc. Doctors acknowledged the inadequacy of pain assessment practices but this was balanced by justification of their focus and vigilance regarding assessment of disease progression and activity. Eccleston et al's (1997) study of health professionals' understanding of the causes of (un-defined) chronic pain identified a common theme of responsibility, whereby professionals' appeared to deflect the burden of responsibility for the patient's pain, shifting this back to the patient, in order to protect their own identity. In this study, responsibility for pain did not appear to be entirely shifted back to the patient. Instead, the rheumatologist appeared to identify his or her responsibility in a limited and defined way. Their responsibility, they implied, was to manage pain through disease assessment and by use of the best available medical treatment to control disease; work which could be supported by objective clinical tests and measures of disease activity (e.g. ESR, x-ray etc. van Gestel and Stucki, 1999). The focus upon disease activity in RA assessments is reflected in management guidelines, which highlight the key role of determining disease progression and effects of treatments (Kwoh et al, 2002). This emphasis is supported by the few existing reports of patients' reflections on consultations. These suggest that patients think that rheumatologists concentrate on the physical dimension of the disease (Ryan, 1996) rather than attending to the problems arising in the patients' daily life (Donovan, 1991).



The problem arising from emphasis upon disease assessment is that pain in RA is only moderately related to disease (Coster and Bengtsson, 2001; Smedstad et al, 1995; van Lankveld et al, 1993), in some instances showing no apparent relation to disease measures (Groarke et al, 2004; Hewlett et al, 1995). As described in Theme 3R, rheumatologists recognise that the negative impact of pain in RA is ongoing despite modern therapies. However, it is only through effective pain assessment that evaluation of symptom change and treatment guidance can be harnessed to ensure optimal pain management (Turk and Okifuji, 2003). Where pain itself is not recognised as a complex and detrimental phenomenon, which persists despite disease modification (Hurst et al, 1997; Katz, 1998; Woolf and Decosterd, 1999) it thus fails to be identified as a priority for assessment. Correspondingly, where pain is not identified as a priority for assessment in its own right it is likely that there will be a failure to deliver effective pain relief (Rich, 2003, p30). This theme supports propositions made by rheumatologists who have suggested that in routine clinical practice, pain is missed or underestimated in the assessment of the patient with RA (Bellamy and Bradley, 1996; Wolfe and Pincus, 1999).

To explore this hypothesis, regarding missed or underestimated pain, further work would be required to study actual clinical assessment procedures. An interesting research methods might be to compare rheumatologists' perceptions of patients' pain in a particular group involved in a clinical trial which involves extensive self-report and information collection (Boers et al, 1994). This could be contrasted with rheumatologists' pain evaluations which are based upon clinical discussion only. The findings of such a study, if they proved positive for the use of self-report and other pain assessment measures as a valued adjunct to professional clinical assessment, might be the necessary precursor to more thorough pain assessment having a positive impact on pain management in RA.

Another debatable issue connected with this theme concerns the idea held by doctors that some patients may conceal problems from the doctor for a variety of reasons e.g. not wanting to burden the doctor. Few reflected that their own behaviour may support or influence what is said or not said by the patients, most ascribing non-report to the patients' beliefs about treatments or wanting to please the doctor. This is contrary to documentation of the significant influence the rheumatologist has upon patients' perceptions of illness (Goodacre and Goodacre, 2004; Kay and Punchak, 1988). Without appreciation of the significant power and authority of the doctor in interactions (Goodyear-Smith and Buetow, 2001) a doctor may unwittingly be acting as a barrier to pain reporting. Whether or not this occurs cannot be determined from this study but would require direct observation of interactions at the clinic.



### **10.7.3 Theme 5R: Classifying the Pain Response in RA: 'coper', 'non-coper' and 'denier'**

This theme is constructed from rheumatologists' accounts of how they understood patients' responses to pain to vary relative to the degree of pain reported and to their apparent ability or otherwise to adapt to life with pain.

The theme was developed from rheumatologists' talk of their observations of diverse behaviours and complaints related to pain when measures or objective signs of disease appeared similar. The pain responses were clustered into three types and were labelled according to the most frequently used term offered by the rheumatologists - the 'coper', the 'non-coper' and the 'denier'. [See Table 10.7.3 for a summary of the patient characteristics for each 'type' of response.] The basis of the distinction between the different 'type' of patient response was primarily related to rheumatologists' evaluation of the extent of evidence for an organic versus non-organic basis for pain and the degree of disruption/disability claimed or exhibited by the patient. These classifications of pain response were not seen to be relevant in cases where pain was severe and/or acute as pain reports at these times were generally considered to be proportional to disease signs.

**Table 10.7.3 Summary of the Characteristics of the Three Pain Response Categories for Patients with RA**  
**Generated from Rheumatologists' Accounts**

Classification of the Pain Response	Coper (majority)	Non-coper (estimate approx. 20% or less)	Denier (relatively rare)
Typical presentation	Relatively little or non-complaint about pain, a stoical response.  Relatively little report of significant life disruption from pain and appear to have a full life in spite of pain.	Repeated, bitter complaints about pain.  Complain about significant life disruption from pain and disability.	Deny problems and may not present to the doctor for treatment/advice.
Principal modulators of the pain experience	Evidence of disease activity, organic processes as primary modifier of the pain experience.	Organic basis of pain is considered less significant than psychological and social factors.	Evidence of disease activity and psychological factors (denial of having illness).
Difficulties of pain assessment	Patient may conceal or under-report pain and the pain impact upon life.	Difficulty in evaluating why there is a pain complaint (doctor searching for non-biological factors/explanations).	Non-report of pain and difficulties.  Non-attendance at the hospital or GP.
Required treatment or support	Control disease optimally.	Control disease optimally, need psychological, social and emotional support.	Control disease optimally.
Expectation of success in providing optimal relief from pain and suffering	Possibility of failing.	Expectation of failing.	Expectation of failing.
Demand upon resources e.g. time	Relatively low.	Significant. Time consuming for all health professionals throughout the illness.	Minimal in short term and potentially significant in the longer term.
Emotional response of rheumatologists	Empathy and some concern.	Frustration and despondency.	Concern and some admiration.

### 10.7.3.1 The copers

The majority of patients with RA were classified as being 'copers', described as being relatively non-complaining about their pain experience or the consequences of it relative to non-copers. The rheumatologists' evaluation of a typical copers' pain state supports the legitimacy of their symptoms (having objective signs of active disease or synovitis and/or joint degeneration) who, despite this, appear to complain relatively little and behave in a stoical manner. Reasons presented for the seeming indifference of copers to pain and their non-demanding behaviour produced a variety of explanations, which were predominately referred to 'psychological' factors and reflective of factors highlighted in Theme 2R. Similar to Theme 2R, there was no apparent consensus in the accounts about which psychological factors were the most significant there being scant reference to what processes/influences that may support such factors. Most reference was made to the particular way in which the patient thought about their illness and commonly offered descriptions of what the coping-patient might believe related to beliefs about past experiences, treatment and ways of living etc. (see Figure 10.7.3).

**Figure 10.7.3 Rheumatologists' Ideas about why some Patients Appear to Cope Well with Pain in RA**

- The patient believes that they are 'better', relative to when they had experienced a flare or an initial pain state and therefore don't complain.
- The patient believes that they can influence their pain through their own actions e.g. adaptation, rest etc.
- The patient believes that it is more positive and adaptive to focus upon living life and what *can* be done instead of focussing upon pain and limitation (i.e. as a way of living with pain - partially ignoring pain).
- The patient believes that nothing else can be done/offered (i.e. in relation to medical treatment).
- The patient has accepted that the pain will not go away.

Rheumatologists suggested that the basis of these patient beliefs were related to a range of influences i.e. learned through personal experience or were due to a fundamental personality trait or were learned from others. Again there was no consensus or obvious dominant explanation offered. Dr Howard's quote is an example of reasoning

that the 'stoical' approach may be a means of positively adapting to life with pain and contains the opinion that many patients with RA use a type of 'denial' that allows them to focus upon life and not illness:

I think part of that is that some patients learn that it is not possible in many circumstances to eliminate pain altogether. They respond to that situation by a sort of partial denial and feel that the best way that they can get on with life is to actually deny the..., well to take the stoical attitude. [D7 Dr Howard]

Most examples pertained to intro-psychic processes i.e. the nature of the patients' own beliefs and how these changed with personal experiences or were part of an inherent trait, rather than making reference to how these may be predetermined/shaped by social or cultural dimensions.

The clinical work of pain assessment with 'copers' was considered to be made more difficult by their tendency to under-play or conceal their pain-related concerns and difficulties. Their acceptance and expectation of pain combined with little belief in the efficacy of treatment was considered to be a barrier to pain reporting, thus risking the under-treatment of pain.

The patients ..can be incredibly stoic and they sometimes lack belief that any thing can get better, .. they just don't believe that anything can improve and so they are not demanding , not as demanding as they should be and it's sometimes difficult to gear them up to expect more. [D13 Dr Parker]

For copers, some rheumatologists advocated an assessment approach using probing, sensitive questions - 'to peel off just a couple of layers to make sure they are not in denial' (D12 Dr Mullins) and so gain some insight into the existing quality of life, its limitations and the degree of potential suffering (already described in Theme 4R). As Dr Elis reports, "good copers with rheumatoid arthritis..., think that it is 'normal' " to live with daily pain and limitation. As described in Theme 4R the need to assess disease activity was not neglected for this group, acknowledging the 'reality' of patients having a progressive disease and doctors having a responsibility to control disease irrespective of the lack of complaint or distress from patients. Since rheumatologists 'knew' that the patient had a progressive disease, despite their attempts to 'play-it-down' and despite the difficulties copers caused in fathoming pain, they were regarded with some admiration for their stoicism.

### 10.7.3.2 *The non-coper*

Four rheumatologists were asked to estimate the percentage of patients they would consider to be non-copers (after the point in the study when the theme had been developed enough to describe/identify it), estimates varied from 10% to 20%. Doctors did not assume that there was no organic basis to their pain experience but they did say that clinical, objective evidence of pathophysiological/structural nociceptive pain mechanisms was judged to be inadequate relative to the degree of pain, distress and disability claimed. Instead, psychological and social factors were considered to be implicated in mediating the pain response observed.

Explanations for this type of response to pain were varied and lacked consensus, there appearing to be more of a 'mystery' element involved than in presenting explanations for copers. Explanations revealed components of different psychological and social theories e.g. pain behaviour being related to secondary gain. The non-coper was presented in a different light from the coper, having a different set of, mainly passive, beliefs. The most commonly reported of these patient beliefs (from rheumatologists' accounts) were:

- patients' belief that it is the 'job' of the doctor to do something to take away the pain (i.e. to find a cure or control); and
- patient's belief that as an individual, there is nothing that they can do nothing to change their pain experience.

Factors presented as possible 'shapers' of this non-coper response, other than through learned pain behaviours from the family, were personality traits and socio-economic deprivation:

In the clinic you know you, have some who can cope better than others. So basically it is a multitude of factors but I think, eh, your ability to cope on the whole is, stronger personalities, more positive thinkers, optimistic thinkers, probably feel..; well at least superficially, I don't know how they feel, they feel a bit better. And the way we know that, they are still happily married, they are still doing some work, they are trying to do the gardening, they try and they don't give up. The ones who are most affected; at least again from the superficial aspect that we see, are the ones that give up and think that there is nothing that can be done and become very despondent and desperate. Now there is no doubt that pain is the driving force but the situation is complicated by, how should I say, less resistance by the individual to his adversity than others. [D15 Dr Whitehall]

The assessment of the pain experience for non-copers was considered most challenging, as the perception was that psychological, social and personal issues (and not organic factors) were a significant part of the 'problem'.

Rheumatologists considered that they had neither time nor expertise to fathom the extent nor nature of these non-

organic factors in a case where the non-coper was demanding help and support. Rheumatologists dealing with the non-copers appeared to be overwhelmed by the variety of possible issues feeding the pain experience and being equipped with only a basic set of simple questions (Theme 4R). It appeared that, at times, they were at a loss to determine the 'cause' or basis of the pain response and so to enable a plan of action to be formulated.

The non-coping patient was perceived to be demanding and consuming a disproportionate amount of resources in terms of staff time. The emotional response to this group by professionals was not as positive as for copers, for all of the above reasons. Additionally, frustration was expressed by doctors that they were not equipped to deal with this group of patients. They were despondent about their lack of resources to deal with the nature of the non-copers psychological and social problems. This was compounded by the belief that any attempt to support these patients would ultimately fail. Figure 10.7.3.2 presents a quotation where copers and non-copers are described/contrasted.

**Figure 10.7.3.2 A Rheumatologists' Quotation Integrating Comparison of the 'Coper' and 'Non-Coper'**

.. the conflict that arises within my practice is that I look at somebody and I think well you are doing ok, but they have got more of a disability than I can detect clinically. For the vast majority there is usually a very good concordance [between his observations and pain report], for the far end of the disease [late disease] there is a very good concordance between what I assess and what the individual says and often.. that transaction process goes relatively easily. The conflict arises.. at the other end of the spectrum, where I evaluate and say 'That's not bad disease you know', there are two or three joints [affected], the ESR is ok.... you know your x-rays are not showing a lot of progression of erosive disease' but God you are moaning like hell [exclaims]. So these patients are a bigger problem for us, or for me. **I:** thinking about that type of person, why are they greater work for you or more difficult?

**Dr Walls:** they are greater work because largely you have to spend a lot of time trying to tease out where the issues are arising. You don't know whether what they are reporting as pain, is often a report of helplessness or whether what they report as pain is because there are several different issues that they have got to deal with. And em, often just saying 'I'm in pain', is the easiest way of saying, 'Well, at least this way, can't you see that I'm knocking on your door, can you give me help?'. And I just don't have the skills, and perhaps I don't want to acquire the skills of trying to help that kind of individual. [D8 Dr Walls]

### **10.7.3.3 The denier**

A small proportion of patients were classified as 'deniers' i.e. those who had been diagnosed with RA and had objective signs of joint damage and synovitis, but who denied there was any real problems regarding pain or limitation. These individuals appeared to choose to live life as if they did not have RA and the rheumatologists suggested that many would probably not consult them. The rheumatologists' concern was that in the long term, unless they took some responsible action to accommodate and/or control for illness, they would further damage joints or exacerbate their condition. These individuals were admired for their courage in trying to live 'normally' in spite of the illness but this admiration was overshadowed by concern for their long-term health and well being. Rheumatologists' main aim, as with copers and non-copers, was to control the disease as well as circumstances allowed.

And then there are those at the opposite end of the spectrum, who absolutely do not accept the fact that this [RA] should limit them. And they over-live and they do not take any cognisance of the fact that they have an inflammatory disease, which damages things. And these are the characters you find phoning you from half way up the Cairngorms saying 'I've got a bit of a swollen knee here'. What can you say, 'Do you want to crampon up here to deal with it?'. And they are the kind of people who are somewhat irrepressible who you kind of admire but you would just like to calm down a bit. [D12 Dr Mullins]

### **10.7.4 Summary and Discussion - Theme 5R**

Rheumatologists appeared to classify patients' pain responses into two main types: the copers and non-copers. The basis of this differentiation is the doctors' evaluation of the degree of pain, distress and disability presented relative to their evaluation of what components of body and/or mind, contribute to the presented state. Copers were identified as those who made few demands and yet presented with objective evidence of disease. The doctors anticipated they were experiencing pain but stoical behaviours were observed. In contrast, non-copers were characterised as overly complaining about pain and limitation relative to the observed organic basis of the reported pain. Non-copers' pain response was attributed to multiple, interacting psychological, social, circumstantial or personal factors which were often considered neither amenable to comprehensive evaluation nor responsive to the support the clinician could provide. The majority of patients were considered to be 'copers' and were generally viewed as being less problematic than the minority of demanding, time consuming 'non-copers'.

However, doctors were concerned that the stoical, copers might have a tendency to under-report pain and/or difficulties, thus leading to the under-treatment of pain.

There are few studies reporting how doctors think about their patients and their presenting problems in relation to clinical work. However, health professionals are known to classify patients into 'typical' categories (Bower, 1998; Bowler, 1993; Stein, 1986) thus helping to organise an appropriate approach or action (Berger and Luckmann, 1967; May et al, 2004), these parallel and support the findings detailed in this section of this study. This in turn concurs with other reports which show that doctors evaluate patients' complaints and their persona as an adjunct to the observed physiological bases of their complaint and/or clinical presentation (May et al, 2004; Stein, 1986). Those with an obvious and measurable organic basis for their pain report appear to be judged favourably but those without such positive signs can sometimes be classed as malingerers and/or difficult and frustrating to manage (Stein, 1986; May et al, 2004).

The differentiation between body or mind associations with reported pain, in 'typing' the patient, is reported in a study of pain experts' evaluations (Vrancken, 1989) and is believed to reflect the dualistic, medical conceptions of pain (Bendelow and Williams, 1995). In clinical scenarios, where biomedical signs do not concord with the patient report (i.e. biomedical correlation between sign and report fails) the significance of pain becomes ambiguous (Sullivan, 1999). This was apparent in Theme 5R. There is justification for attempts to delineate the causes of pain, as Gamsa (1994, p24) states, "Thoughtful separation of mind and body remains a legitimate conceptual convenience, facilitating the continued search for the multiple causes of pain". However, it would appear that the rheumatologist, who is cognisant of the inherent complexities of pain (Theme 2R) is faced with a difficult task in deciphering pain at the clinic (Theme 4R). Limited resources in terms of instructive ways and means to assess and manage pain act as barriers to pain management. Simplified 'typing' of the pain response may have become the 'reality' in clinical work. However, this approach is not likely to be sufficiently sensitive to be useful in guiding effective assessment or management but it may be an approach which matches in its degree of sensitivity the limited options available for intervention (discussed in Theme 6R).

May et al (2004) underlined the importance of the doctors' view of the options for patient 'disposal' i.e. intervention/treatment. Where the doctor believed such options were limited in what they could do for the patient's problem then this belief affected the doctors' empathetic response to the patient. For example, where



treatment options were few, doctors reported feeling frustration (May et al, 2004). Similarly, this study suggests those limited options for appropriate use of non-pharmacological interventions was associated with feelings of despondency and frustration on the part of the rheumatologists. The lack of such resources as staff and time in the field of rheumatology is documented (Guillemin, 2000, Wolfe and Pincus, 1999). It is suggested that perhaps hospital settings are not the ideal place in which to manage chronic illnesses as they are not best placed to actively involve patients and/or promote education and patient involvement (Brady, 1998; Nichols, 1989). Similar conclusions can be drawn from this study's findings as both patient and rheumatologist groups confirm that patient education sessions are not readily provided in rheumatological care. Only one rheumatology site visited during the study offered patients multi-disciplinary educational sessions and only 17% of patients recruited had received some form of education about RA.

A potential problem was hinted at by a few rheumatologists in the accounts where they remarked that the undemanding, uncomplaining majority might be encouraged by consultants' behaviour to continue in this manner and thus leaving more time for attention to be given to the 'non-copers' (who were perceived to demand/require more time at consultation). Waitzkin et al's (1994) study of doctors' interactions with older people found that the doctor reinforced notions of stoicism and individual responsibility and sidelined social problems. Whether this occurs in RA consultations is not known but presents as a potential area for further work, perhaps using observational techniques.

Another under-explored area is the 'deniers' group or those patients who may choose not to attend the rheumatologist for review. This group was by its very nature not captured in the patient sample of the study and there was concomitantly relatively limited talk by rheumatologists about these patients. Potentially, then, individuals who refuse treatment stand to suffer most from pain and its future consequences if they do not seek help (March and Lapsley, 2001). Without understanding these patients' hopes, fears and expectations little can be done to align appropriate support and advice for them or, indeed, to encourage them to seek help. Finding such a sample group and recruiting them to a study would perhaps be difficult but that does not diminish the future importance of such a study.

### 10.7.5 Theme 6R: Striving in Multiple Ways to Support the Patient with Pain

The essence of this theme is related both to the rheumatologists' perceptions of the support they *aim* to provide, in clinical practice, for the patient with pain, the scope and nature of such support and the limits and barriers encountered in its provision. Broadly, rheumatologists' proposed the 'ideal' and main goal in managing the patient with chronic pain as enhancing the individual's quality of life using a multiplicity of means arising from their own skills and from those of other health professionals. The foundation of this support was based upon treating the disease pharmacologically (linking with Theme 1R) although the breadth of additional interventions/support they attempted to offer, as able, suggested a desire to tackle the multiple dimensions of pain.

.. there are massive areas of need and once you detect an area of need you do your best to plug the gap, but I'm not a psychologist so I don't do it as well as a psychologist. But what one can try to do is to take on board.., you can try and locate what are the major stressors for the patients, what are the issues that appear to really be dominating their thoughts. .. Some of it may simply be common-sense advice. But we have no resources to deal with the psychological components so, if you ask me how much impact we have on it, I suspect depressingly little...it's a glaring omission in the care package that we try to put together. [D12 Dr Mullins]

Table 10.7.5 presents the most commonly identified ways in which the rheumatologists considered they could try to positively influence the patient's pain experience and/or consequences of pain. The provision of advice and information about the disease, drugs and prognosis etc. was considered a vitally important role in shaping the pain experience, with the exchange of information extending beyond the patient to partners, family and employers. This corresponded to their belief that patient's understanding of their condition and pain strongly affects the pain experience and ability to manage their pain (identified in Theme 2R).

**Table 10.7.5 The Most Frequently Offered Accounts of How the Rheumatologist Could Influence Patients' Pain**

Ways the Rheumatologist Could Influence Pain	No. of Rheumatologists (%)
Providing advice, information to patient	16 (100%)
Through medication to treat disease and pain (DMARDs, analgesics)	16 (100%)
Referral to other health professionals e.g. specialist nurse, therapists	13 (81%)
Providing support through listening/empathising	8 (50%)
Drug treatment for depression	8 (50%)
Giving advice, information to family and employers	6 (38%)
Providing written support for financial claims	5 (31%)

Within this theme rheumatologists repeatedly drew attention to the necessity of having a team of health professionals to address the diverse problems and concerns encountered, each professional having different skills and knowledge. The rheumatologists' key role, in extra-medical interventions, was as a co-ordinator of other health-professional input and the evaluation of what would best support the patient at any particular time. In terms of what the rheumatologist could offer the patient, clinical assessment and corresponding interventions followed an ordered pattern within accounts. Interventions designed to moderate disease activity were the primary consideration along with attending to the status of the body e.g. do they need a joint replacement? This being followed by consideration of interventions to address psychological health and where relevant, tackling wider personal and social issues. The doctor appeared to work from a biomedical foundation outwards, looking for alternative ways to support the patient with pain, often hoping to be able to involve other specialists. Figure 10.7.5 presents typical quotations that give a sense of the nature doctors' ordering of potential interventions.

**Figure 10.7.5 Typical Quotations Illustrating Rheumatologists' Ordering of Potential Interventions – Beginning with Biomedical Interventions.**

.. my role is, trying to relieve the pain by whatever appears to be the most appropriate modalities, so if their pain is due to more active disease it would be trying to control their arthritis better, if it is more chronic disease then I'm thinking about rehabilitation, use of analgesics, also I am thinking about agencies which may be beneficial to them, thinking about why their pain maybe particularly severe compared to say the next persons, you know, is depression as issue, or adverse social circumstances putting more strain on them which is making them feel more pain. So in some ways I suppose you are a bit like a co-ordinator, trying to find out what is causing their pain and then looking at, to see what you personally can do in the way of medication and education and what other people can do to try and help, to ease their symptoms. And also I suppose trying to, well part of the education is trying to empower the patient so that they believe that they can do and access when things are pretty bad. [D13 Dr Parker]

.. the disease modifying drug which is used to slow down the progression of the disease, is part of what we deal with, make sure they are having no problems with it and increasing it depending upon how active their joints are. But I always ask, or try to, time permitting, about the level of pain relief and in particular if they have any sleep disturbance related to pain relief. Em, and we would.., or should, all document exactly what analgesics they are taking and how many they are taking each time, and if they take it, if it works.. [D5 Dr Brown]

The degree to which the rheumatologists moved towards providing support and advice for 'non-disease' issues varied, with most stating that ideally they wanted to support the patient as an individual rather than a person with RA e.g. through listening and providing personalised advice. Only one doctor identified that he was more comfortable in dealing with medical issues alone, and that this was what he wanted to concentrate upon in practice, as this was reflective of his training and background (D8). However, within his account he contradicted this position by stating that he supported patients in multiple ways, providing letters to support financial assistance and advice to employers.

The range of examples of supporting patients was diverse, from giving advice about exercise, diet and footwear, writing to employers and social security agencies. This theme emphasised the customised approach to patient care, the rheumatologist striving to consider the needs of the individual at a particular stage of life, adapting to specific events and contexts e.g. providing pain relief through steroid injections before a wedding or holiday which the patient wanted to enjoy with less pain. The multidisciplinary team members were acknowledged for the specialist therapies, support and advice that they could offer. In particular, specialist rheumatology nurses (where available) were identified as being a valuable resource, not only for the roles they could take over from the medical staff, but as knowledgeable staff who could provide the patient with extra time to talk about their concerns and to effectively address these. This was in contrast to the time constrained patient-doctor consultation. Several doctors also acknowledged that some patients may not want to share experiences/concerns with them.

And they [patients] have to see the doctor to see that the methotrexate [DMARD] is at the right level and that things are ok, but that only takes five minutes. Whereas actually, really, what they want is to talk about something that another person, [i.e. the nurse] who perhaps has more skills than the medic anyway, and one of those areas may be pain .. That would be ideal and [patients] maybe then wouldn't feel this pressure that they are under. And also the doctor probably isn't necessarily the most appropriate person to talk to about it [pain]. Some people are very private and don't want to talk about personal matters in their life with the doctor. [D10 Dr Dans]

#### ***10.7.5.1 Patients' own responsibility to manage pain***

As well as identifying ways in which the rheumatologist and the multidisciplinary team could support patients, the patient was seen as having to eventually acquire some degree of responsibility for self-management of illness and pain. Ideally, the patient would take responsibility for their day-to-day activity, have some insight into what might be detrimental to their health and then try to manage and/or accommodate to their pain experiences in a positive way.

Patients must take some responsibility for their own management. I mean at the end of the day you [the rheumatologist] try to control synovitis, in the expectation that that will control disease progression. The way the person is responding to the disease overall and pain..., the global thing, in terms of daily living and so forth, is to some extent their prerogative. I don't dissuade people from doing physical jobs if they want to get on with it, contact sports are a problem in young people sometimes which is silly, to go to risky things when there maybe problems with the next day. But otherwise we [can] just give guidance rather than hard and fast rules. [D10 Dr Dans]

Educational courses run by Arthritis Care provide advice and support regarding living with arthritis was highlighted by only two rheumatologists as being valuable sources of information for the self-management of pain (D5 and D8). Only one department visited during interviews was currently running their own multidisciplinary education group, another had run classes up to four years previously but were discontinued due to staffing shortages.

#### **10.7.5.2 Barriers to providing ideal support**

Rheumatologists commonly identified barriers that obstructed their work in optimally supporting the patient with pain. The lack of time for initial and review consultations was highlighted as a problem along with having to deal with multiple tasks at consultations. As the rheumatologists identified medical issues as their primary responsibility e.g. monitoring disease activity, this meant that time given to the patient for expression of their concerns and to discuss problems was limited. These problems were further complicated by the administrative system since clinic bookings failed to incorporate sufficient flexibility to accommodate longer consultations when needed. On average, the review clinic time was reported as 15 minutes and initial consultations 30 minutes.

.. at the end of the day that is what we are there to do, to slow down the disease process. That is the main thing that we do as a specialised clinic. And anything else around that, thinking about their level of pain and side effects of the drugs. Anything on top of that will undoubtedly go outside of fifteen minutes and you know that you are running late, plain and simple, and so something gives.. and that includes if you have to inject joints. [D6 Dr Brown]

Ninety four percent of respondents said that they believed that having more time to spend with patients would improve their ability to support the patient with pain (see Table 10.7.5.2). In addition, more flexible access for patients to attend clinics for review at a time when they felt they needed review, rather than attending at a date assigned six months previously was seen as important. This would enable problems to be dealt with when they arose, rather than attending when they had naturally abated or become more chronic in nature.

Another problem identified by rheumatologists was the limited access they had to the services of other health professionals, which would ideally be expected within a multidisciplinary team. Most commonly remarked was the lack of specialist nurses and allied health professionals. The scarcity of psychology input and social workers within rheumatology units was also raised by more than half of the sample.

So you are often having to address these things [employment, home life], it is being addressed by, well the doctor,.. you often have to address these things within the context of brief clinic appointments, .. we are not terribly well set up in terms of specialist nurses or other health professionals to take on these issues, It's just left to the doctor in the clinic and then there is not much time to take on these issues. [D5 Dr Bryson]

**Table 10.7.5.2 Rheumatologists' Views on Requirements to Improve Clinical Support for Patients with Pain**

Perceived Requirements for Improved Support for Patients with RA	No. of rheumatologists (%)
Longer consultations or more flexibility regarding the length of time available for patient consultations	15 (95%)
More (any) health professionals i.e. specialist nurses, occupational therapists, psychologists, social workers, physiotherapists	15 (94%)
New system for patient appointments that would allow them to be seen quicker, when they need it	10 (62%)
Greater funding for newer drugs	6 (38%)
More rheumatologists	5 (31%)

Other limited resources mentioned by rheumatologists included - lack of funding for new and more expensive medications, limited non-pharmacological support services for dealing with pain e.g. cognitive approaches to pain management.

### **10.7.5.3 Those for whom all available support fails**

In certain circumstances it was considered that there was little that could be done to further support particular patients associated with a resignation that some did suffer more greatly because of that. Those in this category were, in social circumstances which (the rheumatologists considered) were not amenable to change, those who suffered from disease which failed to respond to disease modifying drugs and those who were classified as non-copers (see Theme 5R).

.. like if something else happens, like a bereavement or there are stresses elsewhere that their pain management goes and their coping strategies go, em and that's when it becomes a real problem because that is when it is more difficult to treat. Because you are not just treating the pain at the time but what else is going on, that is not amenable to treatment. [D6 Dr Brown]

The group for whom all drug therapies fail i.e. there is poor response to disease modifying therapies:

Those that have been through all of the sort of disease modifying agents and either tolerated them poorly or not had a response, well I think that we have got some new drugs but we are struggling to get funding for the newer agents. And patients with resistant disease are usually resistant to multiple therapy. So they remain a small sub-group that we don't have the answer for.. [D1 Dr Carter]

### **10.7.6 Summary and Discussion - Theme 6R**

The rheumatologists' ideal goal in the management of the patient was to promote quality of life and to enable the patient to achieve life-goals despite chronic pain. The clinical reality of medical practice, however, presents as a barrier to that ambition. The nature of support actually given to patients emphasised that, at times, care did extend beyond the biomedical goals of slowing disease activity. Management of the pain experience in RA was portrayed as something that was, ideally, significantly broader and eclectic than a biomedical approach which was simply focused upon treatment of disease. Attempts to support the patient incorporated disease-based interventions, mental healthcare, and provision of information and advice with some additional support through counselling and empathising. The expert could also enlist the help of other health professionals. Reflecting the individual experience of pain, it was emphasised that support offered had to be similarly unique. The ideal of supporting the patient bodily, psychologically, socially and emotionally appeared to be compromised by the limited time available to attend to patients' concerns due to, in part, the inflexibility of the appointment system and the lack of resources. Given the perceived organisational and contextual constraints the rheumatologist tended to focus attention upon their key role as disease expert, attending to disease management, thus displacing other issues e.g. pain. Rheumatologists appeared to want the patient to assume some responsibility for self-management of pain. For those patients with difficult social circumstances, those classified as non-copers or those with therapy resistant disease, there was a resigned belief that there was little the rheumatologist (or their department) could offer to reduce their suffering.

Rheumatologists' ideals for supporting patients with RA and pain were paralleled with the broad principles of chronic illness management, namely, to promote quality of life (Lewis and Dixon, 2004). These ideals were aligned with a desire to reverse all of the negative consequences of pain eloquently described in Theme 3R accounts. Doctors were able to provide examples of a wide range of non-pharmacological means, which they



used to support and advise patients through drawing upon their clinical experience, but, in their day-to-day clinical work, organisational and contextual constraints were seen as real barriers to care. Short consultation times were mentioned by the majority of clinicians as a constraint, limiting time spent in advising and informing the patient. Even when including the additional time patients spent with other health professionals, patients opportunity talk at length with health professionals was seen as inadequate. Other studies of rheumatologists and patients call attention to the issue of limited patient contact time (Donovan, 1991; Guillemin, 2000). In another study, in one 12 minute slot the doctor was found to conduct multiple tasks e.g. prioritising what should be attended to, performing injections, blood tests, writing referrals etc. (Hehir et al, 2001). Rheumatoid arthritis and the treatments associated with it present as real threats to mortality (Green and Deodhar, 2001; Wolfe et al, 1994) and medical-related tasks are likely to take priority over patients' pain expectations.

The majority of clinicians mentioned absence and shortages of health professionals to provide specialist skills to care and support those with pain (e.g. specialist nurses, psychologists). This corresponds to reviews of resource limitations in rheumatology (Gray and Muir, 2002; Scott et al, 1998). Non-pharmacological interventions for pain e.g. education about coping with pain, are efficacious (Robbins et al, 2001; Simon et al, 2002) but the provision of such multi-disciplined educational schemes requires labour and significant time (Evers et al, 1998; Superio-Cabuslay et al, 1996). It is recognised that for the effective delivery of care in chronic illnesses it is essential to have multi-disciplinary teams, self-management support and good clinical information systems (Bodenheimer et al, 2002; Von Korff et al, 2002). This does not appear to be available within NHS rheumatology departments which were represented by the rheumatologists in this study. Only one hospital site visited provided formal, educational sessions for patients. This poses questions about where patients might easily access up-to-date, reliable information which is particular and relevant to their needs and concerns.

Only a few respondents mentioned the limited availability of new biologic agents in the treatment of RA, this probably being a reflection of the limited interview time. This lack of 'discussion' does not reflect the extent of the curtailment of the prescription of these drugs in the UK since a survey of all UK consultant rheumatologists found that over 60% were restricted in their use of these drugs due to funding (there was an additional problem in the infrastructure supporting drug monitoring; BSR (2004)).

In summary, there appears to be a conflict between what is considered ideal care for those with pain and what is done in the clinical 'real world'. Medical choices and actions are known to be bounded by organisational and contextual factors (Bates et al, 1997; Jones et al, 2004; May et al, 2004). Rheumatology clinics would appear to be inadequately equipped with staff, time and resources to provide a broad and eclectic approach to pain management. Nisell's (2002) comments upon running a specialist rheumatology pain clinic was that some patients' pain could not be adequately dealt with in the standard hospital clinic appointment but required specialist attention and pain focussed management. It would seem impossible, given the current resources in rheumatology to approach pain in RA as would be done in a chronic pain management sense, where the aim is to optimally control the pain experience through the use of diverse methods (Clark and Cox, 2002; Kugelmann, 1997). The rheumatologist attends to what he/she knows they can augment or alter, mainly the disease, as opposed to attending to factors which they may feel helpless to influence. Their ultimate responsibility to deal with disease is exercised, in keeping with patients' expectation of the rheumatologist as the expert in drugs and the medical care of the disease (Locker, 1983; Ryan et al, 2001).

There are few studies of pain specific treatments for those with RA, but findings suggest that those considered to have resistant widespread pain in RA can experience pain relief and improved well-being with pain specific interventions (Benjamin and Mounce, 2002). Even a small degree of pain relief can be significant to an individual (Rowbotham, 2001). Although findings of this study suggest that more resources and changes to organisational procedures would improve pain management in RA, further study would be required to support these notions. Study of pain management in RA in regions or countries with different resources would be a valuable adjunct to this.

## **10.8 CORE THEMES AND KEY FACTORS SHAPING RHEUMATOLOGISTS' PAIN MEANINGS**

Similar to any subjective personal meanings, rheumatologists' pain meanings were multiple and varied in relation to particular experiences, circumstances and contexts. None of the rheumatologists had experienced RA themselves and none had close family or friends with the condition, consequently, it was not surprising that they drew upon their extensive experiences of interactions with patients to furnish their pain descriptions and explanations.

Several core themes were found to permeate the major themes and sub-themes:

- Causal attributions of pain to bio-physiological processes;
- The inherent complexity of the pain phenomenon; and
- Compromise in clinical pain management - ideals versus 'real-world' practice.

Extracts from Dr Elis' (D2) interview are shown in Figure 10.8 as an illustration of the typical conflicts between ideals of comprehensive, integrated patient care in contrast to what the consultants' perceive they actually deliver. Ultimately, the broad goals of enabling patients to fulfil their ambitions were constrained by the doctors' limited capacity to decipher pain and provide the support required. The outcome was a tendency to focus upon attending to their primary responsibility i.e. the use of the biomedical tools at their disposal by pharmacologically retarding the disease.

**Figure 10.8 Sections of Dr Elis' (D2) Interview - Illustrative of the Core Themes in Rheumatologists' Accounts**

Ideal Aims of Care in RA

My goal is to try to help patients achieve their aspirations and feel fulfilled .. I think that is our role as rheumatologists, to try and get the disease controlled and get the patients to live a life as full as possible.

Primary Responsibilities and the Biological Basis of Pain in RA

..my top role is to see that the disease is controlled. So all my understanding of the pharmacology of treating rheumatoid and sort of focus on getting the patients into remission as soon as possible and trying to prevent joint damage. And when that aspect of things is sorted em, then you are often left with mechanical damage in these patients, which can generate chronic pain cycles.

Clinical Realities - the priority of disease management

**I:** what do you see as being the main purpose of the review appointment for the patient with established RA?

**Dr Elis:** there are two sets of aims; one is trouble shooting, have they got problems and can we sort them out now? What can we do about them? And, is the disease active, have they got active disease or is there a mechanical problem here? So looking at current problems and differentiating active disease from mechanical problems is what takes up a lot of the return appointment.

Difficulty Assessing Pain at the Consultation and the Limits of Time

..you definitely have to probe for this information [about pain and limited function] because each patient; the good copers with rheumatoid and chronic pain, think that that is normal [to live with pain]. They don't think that they are doing anything out of the ordinary. When the pain becomes chronic I am sometimes amazed at how resilient some of the patients become. And you really have to really push them to find out how much pain they are having. ...I mean we only have fifteen minutes and I'm sure that we don't cover.. we are not comprehensive, and I think we need to prioritise and find out, is there one thing, or one or two things, that we can do something about here today?

(Continued)

**Figure 10.8 (continued) Sections of Dr Elis' (D2) Interview - Illustrative of the Core Themes in**

**Rheumatologists' Accounts**

The Complexity of Chronic Pain

**I:** For these patients you describe as 'copers', they believe they are doing all right, how are they making that judgement do you think?

**Dr Elis:** I don't know what the answer to that is really. I haven't asked specifically, but thinking about common enough examples, I know that the patients tend to know their own limits, patients say to me, 'I know my own limits doctor, I will do this, this and this, but I won't do that'. And I think that those limits depend upon levels of fatigue and pain that they are experiencing. It is an emotional thing as well, but I haven't really properly tried to ascertain that from different patients, and that's the best I can answer that question.

The Realities of Clinical Work - failing to provide the best support for patients

Sometimes I think, with review appointments we are just doing crisis management with some people. What we really want to be doing is disease prevention and teaching coping skills so that people don't reach crisis. So that would be the ideal management strategy rather than dealing with the biggest problem today, which is what we tend to use our time to do in clinic.

..[for the non-copers] we try to give them some sort of handles to try and catch on to in terms of directions which they can take which will lead them to better coping. But over years of experience I am not sure that we are very successful in doing that for those sorts of patients.... It is em, difficult to separate the emotional disturbances from the pain and the disability.

The Ideal Scenario

I think, what would be very useful would be to have the patients fill out questionnaires before they come and have them analysed and scored for us [laughs, to imply 'this will never happen']. If we could get them all through... measures of function and perhaps an overall measure of health and mood as well. So we could get a lot of information from all the questionnaires and have it set up in front of us and then we could highlight the areas they are struggling in. And then when we see them in the clinic we could focus on the areas they have told us that they have got problems in and we can, you know, we could allocate time to those things.

### **10.8.1 Causal Attributions of Pain to Bio-Physiological Processes**

Rheumatologists' views of pain as being a symptom of disease processes and/or related to the degree of structural joint damage, are reflective of reductionist, pathologically centred pain attribution. This linear thinking, associating pain experiences with biological status was manifest in accounts covering:

1. the use of pain diagnostically;
2. pain assessment supported by laboratory measures of disease activity or imaging of the body; and
3. reference to pain management mediated by interventions designed to slow the disease.

These causal attributions of pain to the disease is reflective of western societies' understanding of pain (Aldrich and Eccleston, 2000; Rey, 1993; Scarry, 1985) founded upon the dominant, biomedical view of pain (Morris, 1991). This organic model of pain is likely to be based upon the scientific logic developed in medical and

professional training (Kleinman, 1980). Rheumatology is a branch of medical science concerned with the study of rheumatic diseases (i.e. painful disorders of the joints, muscles and/or connective tissue, Collins, 1998) and the physiological basis of pain in RA is emphasised in rheumatological texts on RA diagnosis, assessment and treatment (Dessein et al, 2000; Kwoh et al, 2002; Rice and Pisetsky, 1999). This agrees with studies which suggest doctors causally link pain to tissue damage (Priel et al, 1991) and often fail to appreciate the potential for pain in the absence of nociception (Loeser and Melzack, 1999). These may be reinforced by the clinical observations of the rheumatologist that when patients' experience a flare or exacerbation of their symptoms this relates proportionally to disease measures. However, in RA, as with other chronically painful states, biological or physiological factors can become secondary to social and psychological factors in mediating pain (Melzack, 1999). This is reflected in the movement of current pain theories away from the simple, specificity model towards integrated, systems theory of pain; pain being understood as a dynamic phenomenon, shaped by multiple elements (Keefe and France, 1999). The strength of the relationship between social and psychological factors and pain reports in RA are well documented (Keefe et al, 2002b), along with the relatively small association between laboratory measures of disease activity and pain (Coster and Bengtsson, 2001; Hewlett et al, 1995). The pitfall inherent in adopting a bias towards disease processes being the fundamental factor orchestrating pain in RA is that a corresponding emphasis upon modifying disease as a route to modifying pain will fail (Thompson et al, 2001).

Although this 'disease-model' of pain is at the heart of this core theme, rheumatologists' accounts revealed a parallel appreciation of some wider, non-pathophysiological or non-nociceptive issues in RA. In light of this, the emphasis upon disease as the foundation of pain, may not so much be related to a naivety or lack of knowledge about the mechanisms of chronic pain but may reflect the doctor attending to the dimensions of pain that 'fit' with the medical solutions and interventions that they have at their disposal (Kleinman, 1988; Toombs, 1992). This proposition is further supported in the core theme dealing with compromise in pain management in clinical practice, which calls attention to the discrepancy between what the rheumatologist would ideally like to offer the patient and what they perceive to be available.

## 10.8.2 The Complexity of Fathoming the Pain Phenomenon

When rheumatologists gave accounts of the factors which they believed could influence patients' pain experience in RA, a wealth of non-disease factors emerged, a mixture of views, some stated confidently e.g. depression, others presented like hunches or guesses e.g. genetics and personality. Reflection upon clinical experiences generated talk about the difficulties of attempts to fathom or dissect-out the basis of patients' pain experiences, complicated by appreciation of the inherently personal nature of pain. It was evident from such accounts that the pain experience and response of the individual was viewed as something much more complex than simply a symptom proportionate to the measurable extent of disease. The diverse social, psychological and contextual factors presented in the accounts of doctors lacked any ordering or sense of being integrated via a model or consistent explanatory system (unlike their pathophysiological pain explanations). It is suggested that this lack of consensus and consistency about the totality of factors moderating pain is detrimental to a full understanding of pain and may negatively impact upon attempts to make sense of patients' pain.

There are few contemporary studies published enabling comparison with these findings, and none involving rheumatologists. Eccleston et al's (1997) study of pain experts' views on the causes of undefined chronic pain found that pain experts agreed - their model of pain reflecting an illness behaviour model of pain (Hanson and Gerber, 1990). An older Dutch study by Vrancken (1989), also with pain specialists, identified five different approaches to pain i.e. somato-technical, dualistic, behaviourist, phenomenological and consciousness. Findings of these studies are likely to reflect the pain specialisation of the professionals sampled including their specialist knowledge and their use of alternative models of pain. In contrast, rheumatologists' training and practice is biomedically based (Ramos-Remus et al, 2000) and it is notable that undergraduate pain training lacks the structure and coherence at medical schools (CSAG, 1999). This may explain why rheumatologists predominately presented accounts of a pathological, medical approach to pain (Armstrong, 1995) as this is the model of pain in RA with which they will be most familiar. These bio-physiological mechanisms were frequently accentuated as the basis of the pain experience, with non-disease factors left in a 'catch-all' cluster of variables.

Although significant advances have been made in terms of the basic science of pain mechanisms, the clinical work of pain management remains ambiguous and complex (Woolf and Decosterd, 1999). The biopsychosocial model of pain is promoted as the alternative model to the biomedical model, suited for understanding the biological, social and psychological dimensions of pain (Keefe and Bonk, 1999). However, the lack of reference

to this model by rheumatologists suggest it is perhaps less than useful in the clinical context, a supposition supported by others who advance the view that the model fails to aid clinical decision making (Clark and Cox, 2002; Sadler and Hulgus, 1992).

The complexity of clinical work and its associated reasoning processes which extend beyond evidence based medicine, medical history taking and examination, remains under explored (Jones et al, 2004; May et al, 2004). The findings of this study imply that, although rheumatologists were aware of many of the diverse factors influencing patients' pain experiences, their lack of a clinically useful model or method to frame pain was a barrier to its comprehension; additionally, there was a background of commonly understood constraints regarding available resources and organisational structure and support. This may have driven rheumatologists towards simplistic and familiar dualistic 'typing' of patients into two types, 1. those who had evidence of a significant biological basis to their pain (the copers) that was amenable to the medical interventions they had at their disposal and, 2. those who appeared to present with significant social and psychological issues, which they felt unable to fully address (non-copers). The significance of not having a model or means to aid assessment of chronic pain is the possibility that evaluations are insufficient, interventions may not be entirely suitable and thus treatment fails (Turk and Okifuji, 2003). The American Pain Association's Guidelines for the assessment of pain in RA (Simon et al, 2002) propose multiple measures and questions. However, these guidelines could not be incorporated in the average 15 minute review appointment and, even if the guidelines could be implemented, it appears that there exists insufficient resources to address the problems thus discovered.

### **10.8.3 Compromise in the Clinical Management of Pain: ideals versus 'real-world' responsibilities**

Issues of limited resources and the barriers to care imposed by organisational factors pervade all other themes and, in particular, issues of pain assessment and pain management. Rheumatologists' accounts of how they would 'like' to support their patients with chronic pain when compared to their explanations of what they had actually achieved in practice were illuminating and punctuated with repeated accounts of scarce resources, scarcity of staff, drug availability and the limited time available to spend with patients. Additionally, the inflexible scheduling of clinic appointments was perceived to obstruct optimal care whilst the lack of dedicated staff trained to collect and/or collate patient-generated data was a barrier to comprehensive assessment.



The organisational and administrative structures of healthcare are known to influence patient experiences (Griffiths, 2003) and medical choice is circumscribed by such factors (Bates et al, 1997; Entwistle et al, 1998; May et al, 2004). There are a few studies that examine the influence of the clinical experience upon pain meanings but none were found relating to doctors' pain conceptions in rheumatology. Shortages of staff (Guillemin, 2000; Scott et al, 1998), drugs (BSR, 2004) and limited time for consultations (Stowers et al, 1999) along with limited provision of patient education and advice (Gray and Muirie, 2002) are documented in the literature, but none of these has been associated with pain care.

This study does provide a number of novel findings regarding conceptions of pain management in RA related to the clinical context. The significance of the above mentioned constraints is that given the complexity of tasks that the rheumatologist generally has to perform at follow-up consultations (Stowers et al, 1999) there is little time available to deal with pain. Rheumatologists' identify their key role as controlling disease activity with disease modifying drugs and this is emphasised within guidelines for RA management (Kwoh et al, 2002). Faced with limited time and resources, the doctor is likely to have to narrow their focus and deal with those issues, which are deemed to be fundamental to their expert disease management role. The consultant must also attend to medical issues threatening patients' morbidity and mortality. Given these circumstances, pain management may be compromised or at least relegated to being of secondary concern.

The situation described above does not appear to serve the best interests of the patient with regard to optimal care, effective reduction of pain and support for living life with pain. It is probable that this is not an 'ideal' situation for the health professional either as is illustrated by the generally 'gloomy' view of the rheumatologists have with regard to their capacity to improve patients' quality of life. The doctors appeared to want to assess and manage pain comprehensively and be responsible for supporting patients in multiple ways but they perceived they could not, culminating in frustration and despondency. This is not unlike doctors' emotions when dealing with patients with non-defined chronic pain (Baszanger, 1989; Eccleston et al, 1997; May et al, 2004; Sharpe et al, 1994). The desire to adopt a broad 'biopsychosocial-type' model of care appears to be present but it is blocked by lack of resources, lack of time and limiting organisational factors and thus warrants further and early study.



#### 10.8.4 Key Factors Shaping Rheumatologists' Pain Meanings

Educational background and training is known to influence individuals' perspectives regarding chronic pain (Eccleston et al, 1997; Rainville et al, 1995), although, within any one profession views can also vary between subjects (Rainville et al, 2000) as was found in this study. There are no comparable studies of rheumatologists' pain perspectives however; rheumatologists' conceptualisation of pain in RA is reflective of medical training and the biomedical model of pain associated with this (Hanson and Gerber, 1990). Rainville et al (2000) reported that educational level made no difference to health professionals' views on chronic pain and, similarly, in this study, neither the seniority nor the number of years working experience appeared to influence the nature of the pain accounts generated.

Some studies suggest that the nature of the clinical experience of doctors can shape their perspectives on disease and its management (Marteau and Baum, 1984; Törnkvist et al, 1998). This finding was also evident in this study where those doctors working with the most socially deprived patients consistently raised the issue of their social deprivation having an impact upon pain, a factor which was not emphasised by doctors working in more affluent areas. Also evident from this study was the way doctors drew upon their historical knowledge of past cases and clinical interactions to illustrate examples, suggesting that these experiences may be a key factor in shaping their pain beliefs. There were no differences between male and female accounts nor were there obvious variations related to age. It should be noted, however, that this study dealt with a relatively small number of rheumatologists and was not specifically designed to investigate similarities or dissimilarities between sub-groups of participants.

Organisational demands and constraints can shape working knowledge (Gabbay and Le May, 2004) and clinical contexts appear to have some influence on the pain conceptions of health professionals (Bates et al, 1997). Bates et al (1997) compared healthcare contexts in Puerto Rico with New England and found that each healthcare context had its own values and organisational system which impacted upon health professionals' responses to patients with chronic pain. Vrancken's (1989) study of pain centres in the Netherlands also reported differences in approach dependent upon each centre's philosophy. The most notable difference between various hospital centres and associated accounts in this study was the tendency of the doctors from the same hospital to focus upon their own particular local deficits in terms of the lack of healthcare professionals for example, the loss of psychology services from rheumatology. This suggests that the context and particular resources available to a department or hospital may impact upon views about how pain can be managed at that site.

### 10.8.5 Strengths and Limitations of the Study

Kleinman (1980, p109) cautioned that what doctors' say about their clinical practice may only represent a 'theoretical' explanation and not the functional rationality or thinking that they employ in clinical practice. Being aware of the potential contradiction which might exist between reports of theoretical ideals and actual practice in pain management (Baszanger, 1992) questioning for this study was deliberately probing on the subject of actual clinical practices and the consultant rationale for actions arising.

The study is orientated to view accounts as holding some degree of relative 'truth'; where doctors said their appointments were 12 minutes, this was taken at face value. However, accounts of their explanatory frameworks, accounts of how they actually think at the clinic (and further removed from this), accounts of their actions cannot be determined from this study. This would require an appropriately designed observational study of consultations, supporting interviews and/or the use of vignettes (to explore doctors' reasoning/decision-making regarding hypothetical patient cases). This present study is to be considered as exploratory within this field and there is correspondingly little supporting or comparative work; therefore, the findings of this study should to be regarded as a first step to further study.

It might be expected that rheumatologists would have wanted to present an image of their delivery of good quality care and to project themselves in a positive light (Radley and Billig, 1996). However, the accounts in this study suggest that rheumatologists were open and frank in their descriptions of personal frustration and disgruntlement about the services they are able to provide, both as an individual and as a rheumatological department. The interview could have been viewed as a means of airing concerns with current service provision, anticipating that findings may reach a wider audience through publication. The majority of the rheumatologists knew that the researcher did not have a medical background (but was a physiotherapist) and this may have lessened any inclination they might have had to present overly technical or medical details of care. Not being medically trained may also have lessened any perceived threat of their responses being judged 'incorrect'. The accounts suggested that in general, rheumatologists had presented simplified explanations and these were conducive to comprehending the 'main' message about pain in the limited time for interview.

The use of Atlas.ti® software program (Muhr, 1997) enabled a degree of simple counting across accounts for those questions which were presented to all rheumatologists interviewed thus providing an overview of how

'common' particular views were. This was made possible by the way in which rheumatologists answered questions, in a direct way, whereas patients' accounts were more biographical and unique and exhibited varied and complex patterns. Counting was limited to those areas where questions were consistent and was achieved via through-reading of the individual accounts and not by simply using the software search functions via key words, thus avoiding the complications which can arise when intentions are similar but descriptors vary.

Although no member checks were conducted with rheumatologists, in order that not too much time was requested for participation, this was balanced by the dissemination of the findings and discussion of these with multidisciplinary rheumatology teams at three different regional hospital sites. These sessions provided feedback which supported the key findings of this study, they were accepted as an accurate reflection of the complexities consistent with dealing with pain clinically and of the frustrations arising from not being able to provide 'ideal' levels of support, information and care.

The sample group of rheumatologists would ideally have included some with more disparate experiences and grades e.g. trainee consultants, so as to examine the influence of experience on pain perspectives. However, this proved difficult, as non-consultant levels were generally unable to commit time to the interview due to workload and/or examinations. Although there is a significant variability of experience in the sample group (which did not appear to influence accounts) those with the minimum experience and responsibility might have had different views. The finding that they claimed they were too busy to take part suggests that their time pressures may be even greater than among their seniors, this may have some impact upon their clinical work. On the other hand, the consultant group is important in their own right as they are involved in the education and training of junior staff (several were university lecturers at medical schools) and the patients interviewed talked about their experience with 'their consultant'. The transfer of the findings of this study to those with less experience than consultant level should be undertaken with some caution as further work is required to study pain meanings as they relate to the junior grades of doctors working within rheumatology.

Doctors who worked within more socially deprived areas presented a consistently despondent and negative view about what could or could not be done to support some of their patients. The strength of this positive/negative dichotomy cannot be deduced from this study but its presence does support suggestions that the type of patients seen shapes how the doctor conceives the phenomenon of pain (Askew et al, 1998; Dalton, 1989). Social

deprivation is also associated with poorer long-term outcomes in RA but not necessarily with the report of pain in RA (Hamilton et al, 2001; McEntegart et al, 1997). The need for further work which will examine the relative difficulties or problems presented to those doctors who work with patients from deprived areas versus those working in more affluent areas and the relative demands on services is supported by this study.

It could be argued that those rheumatologists who agreed to take part in this study may have been more likely to have an interest in pain in RA or to believe that it was an important factor in care when compared to those who declined to take part in the study, thus influencing the findings. However, several of those who took part stated strongly that they did not consider pain to be the most important aspect in RA care, thus supporting the case that the sample was not confined only to 'pain-interested' parties.

The sample group of rheumatologists was smaller than the patient-group i.e. nearly half the size. This is not uncommon in qualitative studies and, similar to the patient sampling, doctors were interviewed successively until the point of thematic saturation (Strauss and Corbin, 1990). However, the transferability of findings to other rheumatologists must be undertaken only with the following caveats:

1. It is considered appropriate to extrapolate or generalise the key themes or findings to or for rheumatology consultants working within the NHS and treating individuals with RA at clinics;
2. It is not appropriate to generalise the findings to those rheumatologists of lesser experience than consultant level;
3. It is not appropriate to generalise the findings to those working within contexts where resources or organisational factors are different from those in this study (as outlined in the recent needs assessment for Scotland (Gray and Muir, 2002));
4. Whether rheumatologists' views about pain in RA extend to other chronically painful, organically founded conditions is speculative. As each disease and illness has specific, associated illness conceptions (Weinman et al, 1996) this transference of findings is not credible and it is suggested this would require study of each condition independently.

## 10.9 SUMMARY OF FINDINGS – RHEUMATOLOGISTS’ PAIN MEANINGS

A summary of the key findings are presented along with recommendations for clinical practice and further research in Tables 10.9a, 10.9b and 10.9c.

**Table 10.9a Tabulated Summary of the Characteristics of Rheumatologists’ Pain Meanings and Associated Recommendations for Clinical Practice and Research: shared meanings of pain**

Characteristics of Rheumatologists’ Pain Meanings	Suggestions for Support or Action Required	Areas for Further Study
<p>Pain is predominately related to pathobiological activity and the structural status of the body</p> <ul style="list-style-type: none"> <li>• pain reports can be used diagnostically i.e. pain is a symptom of the disease</li> </ul> <p>With limited ability to control disease activity, pain is anticipated to prevail for the course of the illness</p> <p>Uncertainty about the comprehensiveness of their knowledge of the range of factors which can augment pain in RA</p> <p>Lack of a cohesive way of organising/explaining the non-disease factors which shape pain in RA</p> <p>Compartmentalising the moderators of pain as belonging to either the body or not i.e. ‘other, non-biological’ factors</p> <ul style="list-style-type: none"> <li>• lack of consensus of how non-disease factors shape pain</li> </ul>	<p>Education required</p> <ul style="list-style-type: none"> <li>• regarding the strength of the relationship between pain in RA and psycho-social factors (in contrast to disease activity)</li> <li>• regarding the relative strength of the association between illness conceptions, psychological health, social factors and pain in RA</li> <li>• chronic pain mechanisms and systems to make sense of the multi-dimensional aspects of pain</li> </ul> <p>Increase awareness</p> <ul style="list-style-type: none"> <li>• that treatments to control disease will not always be equated with the best control of pain in RA</li> </ul>	<p>Develop/modify a questionnaire which could address the prevalence of rheumatologists’ knowledge, attitudes and beliefs about chronic pain and more specifically pain in RA.</p>

**Table 10.9b Tabulated Summary of the Characteristics of Rheumatologists' Pain Meanings and Associated Recommendations for Clinical Practice and Research: consequences of pain.**

Characteristics of Rheumatologists' Pain Meanings	Suggestions for Support or Action Required	Areas for Further Study
<p>Pain has a pervasive, negative impact upon the individual's body, 'self', social roles and relations.</p> <p>Pain impact is unique to the individual and their circumstances.</p> <p>Pain is considered particularly disruptive for those who are young, those with dependants and those who are in the early stages of diagnosis.</p>	<p>Increase awareness</p> <ul style="list-style-type: none"> <li>• of the significant burden for patients associated with medical treatments and interventions</li> <li>• of the continued negative impact of pain upon the elderly and those with established disease who continue to experience moderate to severe pain</li> </ul>	<p>More extensive study of doctors' perceptions of the consequences of acutely painful episodes of pain in RA i.e. flares</p>

**Table 10.9c Tabulated Summary of the Characteristics of Rheumatologists' Pain Meanings and Associated Recommendations for Clinical Practice and Research: clinical-contextual pain meanings.**

Characteristics of Rheumatologists' Pain Meanings	Suggestions for Support or Action Required	Areas for Further Study
<p><b>Assessing Pain</b></p> <ul style="list-style-type: none"> <li>• Difficulty deciphering patients' chronic pain experience using a limited number of simple questions</li> <li>• Pain reports potentially concealed by the patient – lack of consensus about why</li> <li>• Perception of limited time for pain assessment with no staff or tools to support the assessment</li> <li>• Primary focus upon assessment of disease variables and body status rather than more complicated non-disease factors</li> <li>• Belief that pain assessment at the clinic is inadequate</li> </ul> <p><b>Classifying the Pain Response</b></p> <ul style="list-style-type: none"> <li>• Simplistic typing of the patients' response to pain relative to objective disease indicators and related pain reports/complaints</li> <li>• Non-copers – show lack of evidence of organic basis for pain, difficult and frustrating to manage with available skills and resources</li> <li>• Copers – present as non-complaining in spite of signs of disease, may have pain under-estimated</li> <li>• Denier – may not seek any treatment nor comply with treatment/advice</li> </ul> <p><b>Supporting the Patient with Pain</b></p> <ul style="list-style-type: none"> <li>• Striving to provide 'ideal' comprehensive, integrated care</li> <li>• Limited by barriers i.e. time, staff, interventions, organisational factors</li> </ul>	<p><b>Education required</b></p> <ul style="list-style-type: none"> <li>• Practical clinical pain assessment methods (and their usefulness in promoting effective pain management)</li> </ul> <p><b>Support required</b></p> <ul style="list-style-type: none"> <li>• Healthcare professionals sharing in pain assessment tasks</li> <li>• Support/advice to manage patients who appear to have complex psychosocial issues augmenting pain</li> </ul> <p><b>Increase awareness</b></p> <ul style="list-style-type: none"> <li>• Of the potential negative influence of the health professional on patients' non-report of pain</li> <li>• That disease measures are often not closely related to the pain experience</li> <li>• That pain is a priority for treatment for patients</li> </ul>	<p>Further investigate the actual clinical assessment practices of rheumatologists through observational study and/or the use of a structured questionnaire (potentially modifying existing questionnaires (i.e. Bellamy et al, 1998 and 1999)).</p> <p>Observational study of whether patients do discuss different pain issues with different health professionals and the implications of this.</p> <p>Compare and contrast the management of those patients who are involved in clinical trials or other circumstances where pain assessment is more thorough than 'regular' clinics - examine for similarities/differences and relevant patient outcomes.</p> <p>Compare sites where there are different resources for pain management - does this influence patient care and pain related outcomes?</p> <p>Exploration of whether the 'denier' group of patients 'exist' and their needs at different stages of their illness.</p>

## 10.10 CONCLUSIONS – RHEUMATOLOGISTS' PAIN MEANINGS

In-depth, qualitative exploration of rheumatologists' pain perceptions associated with RA is a new area of inquiry or at least it is one that has not previously been documented. Research sub-aims directed the study towards describing rheumatologists' pain meanings, exploring what factors might influence these and relating the findings to rheumatologists' clinical pain management work in RA.

Rheumatologists strongly related pain in RA to nociceptive activity underpinned by their understanding of pathological mechanisms in RA i.e. inflammation and joint degeneration. This reductionist, disease-based model of pain is reflective of biomedical thinking and is likely to relate to rheumatologists' medical training. Although this model of pain may be useful for comprehending acutely painful phases of the illness this model represents an oversimplification of the chronic pain in RA which can vary independently of disease activity, for example, being modulated by diverse psychological and social influences (Keefe et al, 2002b). Further exploration of pain meanings revealed that through their clinical experiences of managing patients' with varied presentations and responses to pain, rheumatologists appreciated that wider, non-pathological factors shaped pain; although, the somatic factors were always considered as primary. These 'non-biological factors' were deemed problematic to fathom in the clinical context, there being no apparent consensus in doctors' accounts about the methods or means that they could use to understand and assess the complex, subjective pain phenomenon. The lack of a clinically applicable and useful, analytic framework to understand pain has been noted in the pain literature (Clark and Cox, 2002) and the findings of this study support this. Rheumatologists appeared to be relatively unarmed with any tools or systems to decipher patients' pain presentation, presenting the clinician with a difficult and frustrating task. The findings suggest that the rheumatologist may fail to appreciate the magnitude of the influence of psychosocial factors upon pain in RA at all stages of the illness along with the relative lack of relationship between disease measures and pain (Coster and Bengtsson, 2001; Flor and Turk, 1988, Hewlett et al, 1995). Based on the study findings it is debatable whether educating rheumatologists about the state-of-the-art 'pain-RA knowledge' would alter their clinical practice as doctors emphasised that organisational and resource issues were the key barriers to provision of comprehensive pain management in RA.

Shortages of staff, time and non-pharmacological interventions in rheumatology have been previously documented but not in relation to compromising clinical pain management (Gray and Muirie, 2002; Guillemin, 2000; Wolfe and Pincus, 1999). Other than the problems encountered when attempts to understand chronic pain



are made using the biomedical model, the study findings imply that even if doctors were able to fully assess pain, they would not be able to address many of the issues due to organisational and/or resource constraints. These limitations, combined with the multiple medical tasks rheumatologists identified as key responsibilities (e.g. monitoring drug toxicity), appears to 'force' the rheumatologists to reluctantly resign themselves to dealing with the most immediately evident medical threat to the individual, thus compromising attendance to pain. In this way, the doctor is seen to fulfil their medical role, using the medical tools available to them, evaluating and intervening to slow disease activity, whilst admitting they may fail to effectively manage the patients' pain. A resultant tension develops between what the rheumatologist strives to attain and what they perceive they can actually deliver in the clinical context. Ultimately, 'RA – the disease' and its persistence to defy attempts to control it with medications is seen as the primary problem of ongoing pain in RA.

Without any comparable work with which to evaluate these findings these key points must be viewed as a first stage to understanding the complexity of the work that is conducted in the clinic related to pain in RA. Most importantly, this study section suggests that in practice rheumatologists' 'ideals' of pain management and their accounts of what actually happens appear incongruent. This may explain the frustration and despondency expressed by the doctors. Observational study of rheumatologists at work in the clinic and survey of the actual resources and organisational systems would be a valuable development from the findings of this study.

# **11 CHAPTER ELEVEN - FINDINGS AND DISCUSSION: COMPARING PATIENTS' AND RHEUMATOLOGISTS' PAIN MEANINGS**

## **11.1 INTRODUCTION**

This chapter focuses on comparing and contrasting patients' and rheumatologists' pain meanings relevant to the clinical management of pain and to the delivery of patient-centred care. The pain meanings discussed are listed in Table 11.1. Chapters 9 and 10 already provide supporting quotations for each core theme therefore this chapter is predominately in discussion form with the exception of quotations covering rheumatologists' perspectives on analgesics (not already included in Chapter 10). This allows for a comparison of the variety of views on this under-explored subject. Pain meanings are discussed under three headings:

1. The shared meanings of pain in RA (i.e. the significance/connotations of pain);
2. The consequences of pain in RA; and
3. Clinical-contextual meanings of pain in RA.

Conclusions and suggestions for future research are presented in Chapter 12.

**Table 11.1 Pain Meanings in RA – the perspectives of patients and rheumatologists**

	Patients' Pain Perspectives	Rheumatologists' Pain Perspectives
1. Shared Meanings of pain (i.e. the significance of pain)	Strong disease related identity: <ul style="list-style-type: none"> <li>• Pain as chronic, progressive, cyclical, incurable</li> <li>• Pain is expected in RA</li> </ul>	Strong disease related identity: <ul style="list-style-type: none"> <li>• Pain as diagnostic in RA</li> <li>• Pain as chronic with acute episodes, cyclical, potentially worsening, related to mechanical and inflammatory processes</li> </ul>
2. Consequences of Pain	Pervasive, negative impact upon life: <ul style="list-style-type: none"> <li>• Affecting body, self and others</li> <li>• Flares and uncontrolled disease associated with suffering</li> </ul>	Pervasive, negative impact upon life: <ul style="list-style-type: none"> <li>• Affecting body, self and others</li> <li>• Identify suffering with the early stages of illness</li> </ul>
3. Clinical-Contextual Meanings		
Frame of Reference for Pain	A disease-based model of pain was considered relevant to the clinical context and patient-doctor interactions.	Dominant, biomedical model of pain with supplementary social and psychological 'theories'
Aims of RA Management	Primary aim of interventions to slow disease (i.e. treat the cause), pain is a secondary concern	Aim to maintain/improve quality of life, however, the focus of management is directed towards controlling disease (i.e. pain is a secondary issue)
Responsibility for Pain Management	The doctor is responsible for dealing with legitimate or disease-related pain (physical pain), the patient is responsible for managing the consequences of pain	The doctor is responsible for physical, emotional and psychological support of the patient, all pain and distress is 'legitimate' or real
Ways to Support Patients with Pain	Primarily via drugs to slow the disease, using analgesics as adjuncts (which are associated with adverse effects)	Use of a wide range of pharmacological and non-pharmacological interventions e.g. education, advice, medication
Expectations of Capacity to Control Pain	Limited capacity to control pain due to lack of cure and fear of the negative effects of medications	Ideally, significant control of pain can be achieved but, in practice, non-pharmacological options are limited
Influence of the Healthcare System and Clinical Environment	Perception of there being limited time to talk with the doctor as clinics are busy and consultations short	Scarce resources of time, multi-disciplinary health professionals and drugs in addition to inflexible systems for appointments
Personal Response to Pain in RA	Resigned to the belief that they will continue to experience pain.	Frustration that patients may suffer and that they (doctors) cannot offer greater support

## 11.2 THE SHARED MEANINGS OF PAIN IN RHEUMATOID ARTHRITIS

This study demonstrates that patient knowledge of RA incorporates the 'pain - disease' association which is the common medical understanding, thus patients' pain beliefs mirrored the beliefs of rheumatologists' i.e. where pain is constructed as being chronic, cyclical, progressive and not subject to complete medical control. Patients' self-explanations of pain are augmented by the incorporation of 'learned' medical explanations of pain in RA and its treatment. For example, patients may include such ideas as 'flares' associated with intense pain and the cyclical nature of pain in their explanations of pain in RA. This construction of pain meanings probably reflects patients determination to gather maximum information about their condition through their frequent consultation with rheumatologists (Barlow et al, 1999; Neville et al, 1999; NRAS, 2003). As far as doctors are concerned, they strongly identify with the role of information provider, advising patients about the nature of the disease, its prognosis and treatment. This supports the findings of others that health professionals are key information providers (Brown, 1995; Skelton, 1998) and that, consequently, patients hold the rheumatologist in high regard as the primary authoritative source of medical knowledge related to disease management (Ryan et al, 2003b).

The basis of these medical-type descriptions of pain as symptomatic of body malfunction or disease, is typical of accounts in western medicalised society (Aldrich and Eccleston, 2000; Good, 1992; Kleinman, 1992). The problem with this orientation to pain explanation in RA is that it implies a primary focus on the nociceptive and pathological basis of pain in RA. This focus tends to sideline the importance of non-pathological modulators of pain in RA and may also diminish attention paid to the known non-physical consequences such as depression (Dickens and Creed, 2001). The orientation to reductionist, disease-based pain explanation is contradictory to models of care proposed for RA and chronic pain management. These models suggest that care should not be disease focussed but should take into consideration the patients' needs in the broadest sense (Callahan and Pincus, 1997; Foster et al, 2003; Simon et al, 2002). These findings would suggest that the dominant socially available explanations for pain are those most commonly used by patients and doctors, however, further analysis of pain talk from the study suggest that the separate views of both groups of interviewees are more complex and in some areas are divergent in relation to clinical issues (discussed in Section 11.4).

### 11.3 THE CONSEQUENCES OF PAIN IN RHEUMATOID ARTHRITIS

Accounts of the impact of pain in RA generated similar patient and rheumatologist themes. Both referred to the pervasive negative consequences of pain upon the life of the individual, consequences, which gradually extend to affect family members, colleagues and others with whom they interact. The findings of this study suggest that doctors are aware of the degree of patients' suffering, particularly that occurring in the early stages of illness and in those who are relatively young at the time of onset. Patient-doctor accounts differed in relation to talk regarding the pain of a flare, this being much more prominent in the patients' interviews than in those with rheumatologists. This is not to suggest that rheumatologists were not aware of patients' increased suffering during an exacerbation of the disease, but that they may be less aware than they should be that some patients appear to delay seeking help because they hope for a spontaneous resolution. The patients 'wait for resolution' strategy may also be related to their belief that they could not easily nor expeditiously access expert advice or intervention. Where patients 'wait out' their flare experience then rheumatologists cannot be aware of patients' needs at such times. Research into patients' needs during a flare was identified as an appropriate topic for further study (see Section 9.10).

There is some discord between accounts from patients and doctors regarding pain in patients who perceived themselves as being at the end of all treatment options. Rheumatologists did not describe this group as a separate entity and this may be a reflection of the relatively small number of patients who fit this 'category' in the clinical population. As this sub-group of the patient sample has been constructed from the study findings there is no literature to assist in estimating the possible size and/or 'existence' of this as a patient population. However, of the 29 patients in this study, five were categorised as being characteristic of this group i.e. 20% of the sample group. If this sub-population is not recognised by health professionals and therefore prone to the extra suffering arising from the belief that there is nothing that can be done to relieve their pain (and hence the patient does not seek help) it is unlikely that health professionals will recognise them as a group requiring increased (or different) support. It should be noted that rheumatologists were not specifically prompted at interview to discuss pain experiences occurring at different stages of the illness, to prevent overly directing the findings. Useful further work could be built upon the foundation of these findings aimed at discovering whether there is a patient group of resigned 'non-complainers' who appear to be trapped in an enduring state of suffering, not presently recognised by rheumatologists.

The degree of convergence in themes regarding pain consequences for patients (Themes 4, 5 and 6) and rheumatologists (Theme 3R) suggests that patients are likely to be dealt with by a professional able to empathise with their predicament and who understands how pain may affect their lives. Patients want the doctor to understand their illness and to provide empathy and support (Arthur and Clifford, 2004; Ironside et al, 2003), and it is suggested that such understanding and support is associated with patient satisfaction and with an increased sense of control in living with RA (Carr et al, 2003; Coyle, 1999; Ryan et al, 2003b). This may explain, in part, patients' accounts of being generally satisfied with their experiences at clinic despite rheumatologists' stated concern that optimal treatment for pain was not being provided (see Section 10.7.5). In this study, patients gave positive accounts of how they felt they had been 'understood' by their rheumatologist (particularly at the first consultation). Although both patients and doctors suggested that, at follow-up consultations, time was limited, (thus curtailing talk about pain and related concerns) the initial meetings would appear to have conveyed to the patients a sense that the doctor understood their experience. In relation to review consultations both doctor and patient appear to blame the hospital systems for not providing sufficient time for pain issues/problems to be fully and properly discussed. However, it should be noted neither party ascribed any blame to the other.

## **11.4 CLINICAL-CONTEXTUAL MEANINGS OF PAIN IN RHEUMATOID ARTHRITIS**

### **11.4.1 Frame of Reference for Pain**

Patients' pain meanings in relation to medical care and clinical interactions was conceived in a narrow biomedical way (see Section 9.8.1 - Negotiating Pain to Match Perceived Responsibility). Patients' more wide ranging ideas about pain variability and pain as behaviour (see Section 9.6.3 – Pain as a Conflict between 'Real' Body Pain and Private, Subjective Pain) were not considered relevant by them in the clinical arena. In contrast, rheumatologists' wide ranging and loosely constructed pain 'theories', regarding psychological and social modulators of the pain experience, were deemed by the doctors to be relevant to clinical pain assessment and pain management in RA (see Section 10.7.1 – Difficulty Deciphering Patients' Pain Experience at the Clinic and Section 10.7.5 – Striving in Multiple Ways to Support the Patient with Pain). This contrasting view of pain in relation to clinical care and interactions appeared to have implications for pain management aims, responsibilities and interventions.

### 11.4.2 Aims of Management and Responsibilities

Patients presented a biomedically-bound view of the principal aims of RA management and a correspondingly reductionist view regarding rheumatologists' responsibilities. In contrast, rheumatologists viewed the aims of intervention more eclectically, ideally aiming to maintain or improve the individual's quality of life, in line with chronic illness models of care (Lewis and Dixon, 2004; Von Korff et al, 2002). Doctors considered this could (in theory) be achieved through the use of disease modifying drugs and/or with non-pharmacological interventions to support the patient in pain e.g. advice, education, counselling etc. delivered either by themselves or by other members of the multi-disciplinary team. In this way, rheumatologists' broader and looser frame of reference regarding pain modulation was reflected in their various ways of providing support to patients. Doctors accepted responsibility for supporting patients physically, emotionally, psychologically and socially. All of these dimensions were considered 'real' in shaping patients' pain and their ability to live with pain. In contrast, patients presented a more biomedically-bound version of the doctors' responsibility i.e. to deal with the disease and the 'physical' pain arising from the disease, and, perhaps consequently, patients appeared to take personal responsibility for managing the 'non-physical' or psychosocial consequences of pain.

These conflicting patient-doctor views may impact upon talk about pain at the clinic. Patients, in viewing the doctor as a 'disease manager' may restrict more personal accounts of pain impact. Patients are known to present what they think appeals to the doctor at the clinic, wanting to match the validity of their accounts with what they perceive, or have pre-conceived, to be the medical view (Nijhof, 1992; Salmon and May, 1995). This is not conducive to pain reporting and militates against capturing in its entirety a complete understanding of patients' pain beliefs, attitudes etc. (Turk and Okifuji, 2003). This mismatch of understanding may explain, if only in part, doctors' reports of the difficulty at consultation of 'getting to the root of the problem' (see Section 10.7.1).

A patient-centred approach to chronic illness management encourages patient involvement and collaboration with the doctor (Mead and Bower, 2000) but this study suggests that patients and rheumatologists have different ideas about responsibility for pain and the aims of management. Patients need to understand their own role and the role of the doctor in managing them if they are to be a useful source of information in the formulation of effective care (Von Korff et al, 2002). It is suggested from the findings in this study that, in practice, patients need to be

educated regarding their role in pain reporting and so encouraged to give their own accounts of pain and its impact. Health professionals should be made aware that patients with RA might assume that it is their role to bear pain in RA, a disease which all patient participants assumed would become increasingly painful over time. The dilemma in all of this is that the good intentions of the doctor attempting to engage in an eclectic, non-biomedically bound approach may be seriously hampered where patients do not share this view as relevant or expected.

One question posed by the findings of this study is - How do these divergent clinical-contextual meanings come about? They may relate in part to traditional views of medicine and the doctors' curative role (Gamsa, 1994; Rich, 2003) but patients' accounts suggest that they perceive the consultation to be an occasion centred on testing, measurement and subsequent prescription of medications, rather than an in-depth evaluation of their personal pain concerns (see Section 9.6.3.2). Rheumatologists' accounts tend to agree with this as doctors explained that their eclectic ideals of pain management and associated patient-focused assessment were not fulfilled due to limited time available to assess then manage the complexities of pain experiences (see Section 10.7.2 and 10.7.5.2). Although doctors were aware of the diverse range of options for supporting the individual they appeared limited by circumstances, beyond their control, to simply focussing upon the pharmacological tools they had at their disposal which, in turn, is likely to reinforce patients' expectations of pathological-orientated care. In this way, despite doctors suggesting that all reported pain and related distress was legitimate and 'real' they appeared only to be principally equipped with the intention, knowledge and tools to deal with pain which they perceived was disease related. Healthcare systems are recognised as presenting barriers to effective pain management e.g. costs of treatments or lack of service provision (Brockopp et al, 1998; Chapman et al, 2001) and generally circumscribing medical choices (Jones et al, 2004; May et al, 2004). However, this has not been documented in relation to pain and RA and this study's findings pose questions about the capacity for quality pain management in RA in the NHS as presently constituted. Where resources are available for patients (i.e. resources which are outwith the scope of traditional biomedical interventions), patients need to be reached and informed of this, so that they are in a position to ask for help. Otherwise a patient cannot be expected to be a co-healer if they do not understand their options.



## **11.4.3 Patients' and Rheumatologists' Perceptions of Drug Interventions**

### ***11.4.3.1 A brief review of patients' views about medications***

Previous work in RA has identified patients' concerns about taking disease-modifying drugs, which is presently the cornerstone of RA treatment (Fraenkel et al, 2002; Goodacre and Goodacre, 2004; Ho et al, 1998; O'Brien et al, 1990; Park et al, 1999; Pullar et al, 1990). Of this work, none has specifically identified and explored patients' and/or rheumatologists' perceptions of commonly prescribed analgesics. As was reported in Section 9.8.3, the majority of patients had negative views about analgesics e.g. concern about tolerance, and this appeared to be associated with patients' actions to minimise intake of all classes of analgesics (even in circumstances when this may have provided the desired relief from pain). In contrast, patients reported compliance with disease modifying drugs (e.g. Sulphasalazine or Methotrexate) and demonstrated accurate knowledge of DMARD actions and effects. Donovan and Blake (1992) also noted that patients appeared more likely to limit their intake of analgesic medications suggesting this was due to rheumatologists assuming that patients were knowledgeable about analgesics and therefore not supplying them with relevant information and guidance. This suggestion is supported by this study's findings where patients interviewed also appeared not to have been given specific information about analgesics. Subsequently, questions were directed at exploring this topic further when interviewing rheumatologists.

### ***11.4.3.2 Rheumatologists' views of analgesics in RA***

Rheumatologists were aware that the majority of patients used various types of prescribed analgesics, thus confirming patient reports (see Section 9.8.3.1). They considered them an important adjunct to managing pain in RA.

... they [patients] are taking drugs like co-proxamol or tramadol or paracetamol as baseline pain control in addition to their NSAID or DMARD therapy. So pain is something which is important..' [D4 Dr Silvers]

The majority of rheumatologists believed patients did know how analgesics worked and how they should use them to best effect.

I think they [patients] do understand what analgesics do, paracetamol, co-proxamol and co-dydramol and those sorts of things. I think patients are quite good at managing their own analgesics. .. most of my patients take analgesics and most of

them take them fairly well. .... I think that the patients themselves probably know more about what analgesics work best for them than we do. [D3 Dr Adams]

.. with analgesics it is taken more in a kind of.., up to eight times a day depending upon how they feel. So they probably control.., well this is my impression and I don't know if this is true, but I suspect that they control their simple analgesics themselves. [D11 Dr Barbour]

Ideally it was considered that the patient should be knowledgeable about analgesics so as to effectively use them, this being in accordance with the principles of self-management in chronic illnesses (Von Korff et al, 2002).

.. the practice that we try to institute here is that largely the patient should have an understanding of their drugs, why they are taking them, which drugs they can alter and which drugs it would be inappropriate for them to alter. And therefore .. the control of .. analgesics, in my practice, is giving [it] to the patient and saying 'you do it'. The symptom control is something that I let the patient understand and say really, 'you know this is what you can do to control your symptoms'. [D8 Dr Walls]

Generally, rheumatologists suggested that patients were best placed to regulate their use of analgesics, as only they could know their own pain. The doctors did not give as much information about analgesics as they did for disease modifying drugs and this may explain patients' lack of understanding about analgesics and their emphasis upon the importance of disease modifying drugs. The patient can be regarded as the 'expert' in terms of their own pain experience, but the passing of responsibility to the patient for self-evaluation of pain and related actions could be misguided (e.g. in the case of analgesics) where it is assumed the patient will know best how to use them. This study suggests that in some regard the professional's belief in the patients' understanding of analgesics and the use of analgesics is erroneous. Prior (2003) suggested that the vision of the healthcare user as the 'expert' can be taken too far and suggests that the patient needs specific education about things they have not experienced or seen:

All in all, they are experts by virtue of 'having the experience'. Yet, experience on its own is rarely sufficient to understand the technical complexities of disease causation, its consequences or its management. (Prior, 2003, p53)

Patients' concerns about analgesics may influence decisions about whether to take these medicines as patients are known to 'trade-off' beliefs about perceived adverse effects and health benefits in deciding how to use medications (Horne and Weinman, 1999). This study suggests that health professionals need to be more aware of patients' lack of understanding regarding analgesics. When health professionals talk about pain and analgesia it may be useful were they to explore the patient's specific concerns and behaviours related to the use of analgesics. This would allow the health professional to address the specific educational needs of the individual, as opposed to

the assumed needs in written information. Patients' perceptions of health professionals' attitudes may also shape their views about the use of drugs in RA (Goodacre et al, 2002; Goodacre and Goodacre, 2004) and the non-discussion of analgesics may inadvertently reinforce a message that analgesics are not seen by the rheumatologist to be important in the management of RA.

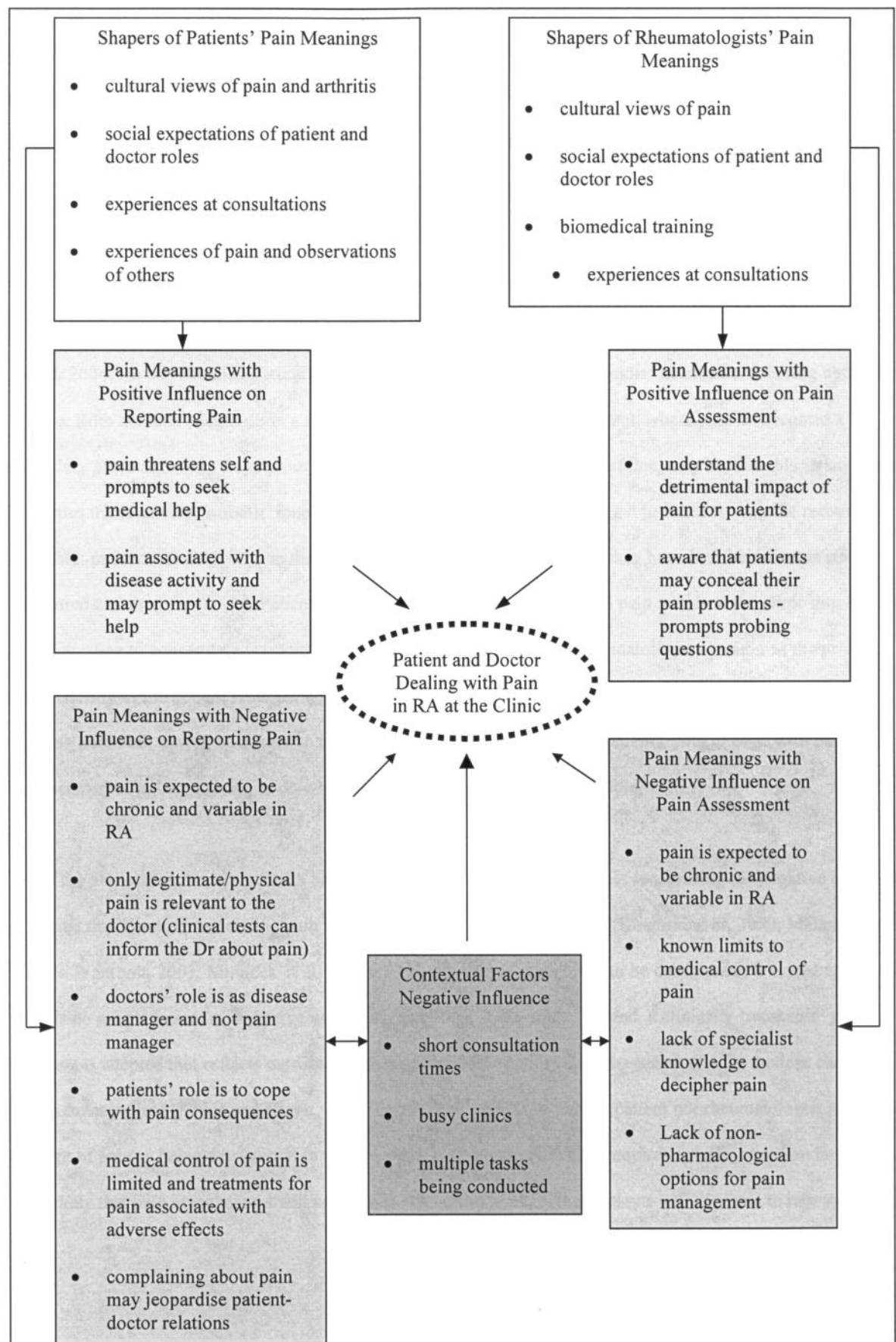
#### **11.4.4 Expectations of Pain Control in RA, Resources and Personal Responses**

Both patients and rheumatologists anticipate long-lasting pain in RA associated with the chronic nature of the disease, lack of a cure or effective treatments able to fully control symptoms. Patients' strongly associated pharmacological inadequacies with limited medical capacity to influence pain, adding to their sense of the inevitability of pain. In contrast, doctors' view of pain control encompassed non-pharmacological interventions e.g. social and psychological support. These responses reflected doctors' accounts of their responsibilities and roles in RA management and accords with evidence for the use of non-pharmacological approaches in RA pain management (Riemsma et al, 2003; Robbins et al, 2001; Simon et al, 2002). Although these expectations about pain control appear to be divergent, both groups were ultimately negative in their outlook regarding pain control. The doctors group findings suggested that their efforts were constrained by the lack of a full multi-disciplinary team compliment, limited drugs, limited time for assessment and organisational inflexibility regarding consultation appointing. As a consequence doctors suggested that the focus of care had to be on essential disease management, thus reinforcing the primacy of medical interventions for pain over all others. These factors were perceived to conspire against managing the patient in accordance with a chronic illness model and erected barriers to the patient becoming an active self-manager of their illness (Helman, 2000, p67). It is suggested that the hospital environment is not conducive to patient involvement (Brady, 1998), underpinned by the historical and still extant ethos of curing in acute illness rather than in educating for living with chronic illnesses (Helman, 2000; Holman and Lorig, 1997). This was manifest in the pain meanings described herein, where the doctor generally had to focus on medical roles due to time limits and resource availability.

The question remains - Who is dealing with patients' personal pain concerns and/or pain consequences when patients deem these are *not* the responsibility of the doctor? The majority of patients reported they would not consider attending patient led formal educational/support groups run by arthritis agencies and did not want to

burden family or friends with their concerns. Figure 11.4.4 illustrates the key patient and rheumatologist pain meanings that may influence pain management in RA. This figure highlights the various patient pain meanings which may discourage/encourage patients from reporting pain and the rheumatologist-perceived barriers to clinical pain management.

**Figure 11.4.4 Key Patient and Rheumatologist Pain Meanings which may positively or negatively affect Pain Reporting and Pain Assessment at the Rheumatology Clinic**



## 11.5 IDEALS OF CARE IN RA VERSUS CLINICAL-CONTEXTUAL PAIN

### MEANINGS

The ideals of patient-centred care are laudable in RA as they direct the health professional away from a disease focus towards individuals' personal requirements to optimally manage life with pain (Mead and Bower, 2000). Sullivan (1999) emphasised that pain related actions or in-action always has a purpose and prompts the researcher to ask the question, what purpose might these clinical pain meanings serve for the patient and doctor? Why do both doctor and patient appear to operate within a disease-focussed frame of reference? Doctors may feel bound to deal with disease related problems as a priority and consequently reinforce patients' perception that this is the doctor's primary interest and role. Patients are satisfied with their care when the doctor behaves as 'expected' (Ward, 2004). In this situation patients' expectations are aligned with the doctors' actions i.e. focusing upon the disease. Both are then caught-up in a self-perpetuating focus on disease-control, where pain is delegated a secondary place as merely a symptom of the disease. The positive outcome of this, may be, that this arrangement facilitates the relatively 'smooth' functioning of the hospital clinic – allowing it to function with the resources available; patients are dealt with in the time allotted and leave satisfied that they have had their disease status monitored and drugs reviewed. Patients do not expect to share their personal pain stories at the clinic thus leaving the doctor free to concentrate upon medical issues that both patient and rheumatologist consider as the primary responsibility of the doctor. Both patient and doctor can then justifiably blame the disease and lack of cure for ongoing pain both having been seen to act responsibly; the uncomplaining patient trying to cope with pain and the overworked doctor striving to do what they can with the resources available.

All of the above must be set against a background of both patients and doctors recognising the negative impact of pain, and the literature associating pain with decreased quality of life in RA (Kosinski et al, 2000; Melanson and Downe-Wambolt, 2003; Minnock et al, 2000). Although pain is recognised to be detrimental, it would appear that there is no means to accommodate personal pain meanings at the clinic. Instead, a clinically 'workable' pain meaning is adopted that reflects outdated biomedical models of pain which are unsuitable for modern chronic illness management (Lewis and Dixon, 2004; Foster et al, 2003). As neither patient nor rheumatologist project a concept of pain as being detrimental in its own right, a phenomenon which requires specific attention in itself, it is unlikely that pain management will advance in RA, and it is likely that patients will continue to rate pain as one

of their primary problems unless this inherent problem is properly addressed (Heiberg and Kvien, 2002; Minnock et al, 2003).

## **11.6 STRENGTHS AND LIMITATIONS OF MAKING PATIENT-DOCTOR COMPARISONS**

The strengths and limitations of this study have been discussed in Chapters 9 and 10 regarding generation of patient and rheumatologist findings respectively. This section is dedicated to the examination of the credibility of comparing 'pain meanings' as they are separately constructed and presented for patient and rheumatologist.

Shaping the research mini-questions for patients and rheumatologists (see Section 8.2) in the early developmental stages of this study enabled similar topics to be explored with both groups. This then became a positive point for the making of relevant comparisons. Similarities in the initial descriptive category lists for indexing the respondents' accounts (Appendices 10.1) also support the comparison of pain themes across the groups. As the doctors' interviews were conducted after the patient findings had been partially analysed this enabled the inclusion, in rheumatologist interviews, of topics which were not previously anticipated e.g. patients' concerns about analgesics. That said, it must be recognised that the interview guides were used in a flexible manner. Pain-meanings were generated via questions, which were partially dependent upon the responses given, so gaining a deeper understanding of the complexities of pain meanings. The implication that not all subjects had identical questions or topics covered in the same detail or in the same sequence is accepted as a characteristic of a qualitative semi-structured interview. As the findings were generated and as themes approached saturation the focus of questioning changed, particularly in the case of rheumatologists since their interview time was significantly less than that for patients. Therefore, it cannot be said that patients and rheumatologists were always presented with the same questions because, despite the relatively higher articulacy of rheumatologists, rheumatologists did not have the same availability of time to expand upon their various points. This limits to a small extent the validity of an 'exact' comparison of the themes generated.

Shorter interview duration for rheumatologists is likely to have curtailed the extent of the pain issues covered, although interview times recorded were considered generous relative to the apparent existing demands upon doctors' time. The lack of literature with which the findings of this study can be compared does, to some extent, reduce the robustness of the findings but this is a phenomenon, which cannot be avoided when research breaks



new ground. On the other hand, health professionals were supportive of the findings when they were presented to multi-disciplinary gatherings and this tended to corroborate the findings in the absence of extant literature. However, it may be that participants at these meetings felt obliged to give positive feedback, some knowing that their department had been involved in recruitment or that some of their rheumatologists had taken part.

To focus upon comparison of patient-doctor pain conceptions and ensure equity of coverage of topics would require formulation of a questionnaire or use of methods to allow the same issues to be presented to each, in a way that would be understood by each. The use of Q-methodology enables the presentation of a range of diverse viewpoints or understandings related to a topic (e.g. pain in RA) in which participants can sort responses in relation to their own perceptions (e.g. agree, disagree, don't know; Corr, 2001). The pattern of the responses from individuals or groups (e.g. patient and doctor) can then be analysed for similarities and differences (Stainton Rogers, 1991, p126-129). This enables the respondent to control what is selected or not and, provided that the set of statements presented to the sample is comprehensive and inclusive of the relevant factors, a large number of people can be surveyed.

Patient and rheumatologist interviews were based around topics of pain uncomplicated by concomitant painful conditions or complications which are relatively common in RA (Chehata et al, 2001; Jayson, 1999). To fully explore pain conceptions in RA and also the complexities of pain issues at the clinic would require a further study of respondents' views of pain when this pain is associated with other painful conditions and complications. It can only be assumed that the complexity of the clinical tasks/actions that patient and rheumatologist engage in (for these more complex illness presentations) will be more challenging than the scenarios referred to in interviews for this study. In a similar vein, doctors and patients manage and discuss more symptoms than pain alone e.g. stiffness and fatigue. To exclude such 'complications' from this study was necessary to allow the generation of detailed findings regarding pain within the time available for the study. However, any holistic view of RA impact and RA management must of necessity incorporate all symptoms and it is only within the context of research that they are 'artificially' separated.

The comparison of pain meanings as separately generated for patients and rheumatologists suggests a consequence for future patient-doctor interactions, understanding and communication. However, any intention to use the findings of this study in relation to 'patient-rheumatologist' interaction is made problematic by the



difficulties in drawing generalised conclusions from each groups' findings. It is acknowledged that simply knowing something of what each group of respondents might 'think' or 'feel' about pain in RA cannot address the many other 'non-cognitive' factors involved in interactions e.g. non-verbal communication, issues of power and situational circumstances. A more complete understanding of the implications arising from divergent pain meanings in relation to communication and/or interactions would involve observational study of pairs of patients-rheumatologists engaged in clinical consultations, including prior and/or subsequent study of their contemporaneous thoughts/views etc.

This study may have been enhanced by 'pairing-up' rheumatologists with their respective patients and examining what each said in relation to each other, as well as across the groups. However, this may have impacted negatively upon the willingness of patients to be open about their experiences and rheumatologists may have felt this opened the opportunity for criticism of their clinical practice. As such, the comparison of meanings generated in this study represents a first stage in the documentation of the issues which may influence pain management in RA in a positive or negative fashion. The use of these findings to explain what happens between patient and rheumatologist in the clinical setting needs to be confirmed by further studies.

## **11.7 SUMMARY OF FINDINGS**

The pain related meanings of patients and rheumatologists were separated into three types, as follows:

1. the shared meanings of pain (i.e. the significance of pain in RA);
2. the consequences of pain; and
3. clinical-contextual meanings (i.e. meanings related to the clinical interventions and interactions).

Both patients and doctors strongly attributed pain to characteristics of the disease i.e. pain was primarily perceived to have a pathological or organic basis and was expected to be chronic, cyclical and not fully controllable. Patients' frame of reference reflected western lay understanding of pain, being a signal of body dysfunction, whereas doctors had more sophisticated explanations drawn from social, psychological and behavioural theories.

The consequences of pain in RA as understood by rheumatologists were relatively concordant with patients' reflections on their experience of pain and its detrimental impact. Rheumatologists appeared to be less aware of patients potential for suffering during acute phases of the disease and in the late stages of the illness than was expected and this is one of the areas identified for further study. Patients' frame of reference for pain with respect to clinical management and consequent interactions appeared to be underpinned and influenced by clinical experiences and traditional views of doctors' roles. This included the doctors dealing pharmacologically with the disease rather than attending to personal or subjective pain concerns. In contrast to this biomedically narrow view, doctors perceived pain and distress as being not always related to disease and ideally aimed to support patients in a variety of ways e.g. psychologically and socially. Views also diverged on the use and usefulness of analgesics. Doctors proffered ideals of eclectic and patient-centred pain management but the findings of this study indicate that they were unable to fulfil these aims due to such limitations as lack of resources and contextual/organisational barriers. Thus, they were constrained to operate an unsupported disease-focused practice in the complex work of managing chronic pain. Because of this, doctors appeared to reinforce patients' conceptions of the secondary place of pain in RA management (relative to the primary focus on disease management) and by this means, sidelining personal pain meanings.

The contribution made by this section of study findings to knowledge of pain meanings and the consequent implications for both clinical practice and future research are laid out in Chapter 12.

## **12 CHAPTER TWELVE – SUMMARY, CONCLUSIONS AND FUTURE RESEARCH**

### **12.1 INTRODUCTION**

This in-depth qualitative study aimed to describe and explore patient and rheumatologist pain meanings in relation to the chronic illness - rheumatoid arthritis. More specifically, the research sub-aims were, as follows: to describe these pain meanings, to explore how the pain meanings might be constructed and compare/contrast patient and rheumatologist views of pain. The purpose of studying pain meanings for patient and rheumatologist groups was to evaluate the similarities and differences and consider the implications for patient-doctor communication about pain and pain management in RA. In addition to this comparative evaluation, the findings from each group can also 'stand-alone', adding to what is already known about patient and doctor pain meanings. Accordingly, the conclusions are presented in three sections, as follows:

1. Pain meanings in RA: patients' perspectives;
2. Pain meanings in RA: rheumatologists' perspectives, and;
3. The different perspectives on pain in RA: patient and rheumatologist.

Within each section, the findings from the study are evaluated for what they contribute to the body of knowledge about subjective pain meanings and the clinical care of the patient with RA and pain. Suggestions for future research to address the current findings and study limitations are presented at the end of the chapter.

### **12.2 PAIN MEANINGS IN RA: PATIENTS' PERSPECTIVES**

#### **12.2.1 Advancing the Body of Knowledge about Patients' Pain Meanings**

Over the past 20 years there has been an increasing number of qualitative studies on patients' subjective meanings of pain, also known as the 'insider' view of pain (Conrad, 1987). Much of this work has focused on patients with un-defined or un-diagnosed conditions e.g. chronic low back pain (May et al, 2000; Osborn and Smith, 1998) with surprisingly little attention given to the study of common progressive conditions (such as RA)

which are known to be chronically painful. Previous 'insider' type studies in RA have tended to explore the illness experience as a whole; hence, there is a lack of understanding about patients' views on *pain* in RA. In comparison, the greater number of quantitative studies of RA have established that, despite the best treatments currently available, pain intensity in RA is rated to be moderate to severe and negatively impacts upon patients' quality of life (Kosinski et al, 2000; Minnock et al, 2003).

This study's findings support the existing literature on patient pain meanings, finding them to be dynamic, diverse and shaped by many factors, for example, socially available explanations, experiences, time and context (Kleinman, 1992). The findings also parallel others' work regarding the consequences of chronic pain where these are found to threaten the patient's sense of 'self' as well as impacting negatively on others around him or her (Honkasalo, 2000; Thomas, 2000). In contrast to the findings from studies of individuals with non-defined conditions, a 'paradox' of pain meanings was apparent in RA patients' narratives. Patients appeared to interweave accounts of acceptance and expectation of daily pain with their narratives about the diffuse negative impact of pain. Explanation for this paradox was illuminated through talk about associations between pain and the disease - RA. The key finding, which is distinct from previous work on un-defined conditions, is that patients' views of pain were shaped by a strong causal attribution of pain to disease processes and their knowledge about key features of their *disease*: lack of cure, lack of effective medical control and uncertain prognosis. Through this understanding, daily pain was expected and anticipated to worsen with time and, thus, was accepted as an inevitable part of life. The notion of 'acceptance' and associated resignation to experience daily pain may be a positive adaptation, enabling the patient to 'get on with life' rather than focussing upon pain (McCracken, 2004). However, the findings of this study suggest that this 'acceptance' is perhaps not well founded as patients have not been exposed to comprehensive pain management advice and support.

The core theme from the patient findings (i.e. the attribution of pain to disease processes) is inter-related with two others: the legitimacy of pain and responsibility for pain. The legitimacy of pain and responsibility for pain emerge as substantive topics in studies of un-defined chronic pain (Eccleston et al, 1997; Howell, 1994; Werner et al, 2004); however, the descriptions and implications appear to be different in RA. Patients with RA appear to accept the greater part of responsibility for managing pain and its consequences with the doctor being ascribed more limited responsibilities, such that, he or she was only responsible for the management of 'legitimate' pain (i.e. that related to disease processes and the physical/bodily consequences of the disease). Patients' pain

meanings generated from talk about consultations were characterised by their narrow and specific biomedical orientation. Related to this reductionist pain-orientation, the rheumatology clinic was identified as a context where the more personal and subjective pain meanings were suppressed and only those issues considered to be 'disease-relevant' were offered up.

The clinical relevance of all of the preceding 'new' pain meanings in RA is that they suggest that despite patients having a recognisable, 'credible' reason for their pain (i.e. the diagnosis of RA), the information gathered about the disease may engender self-questioning about the legitimacy of their own diverse, personal and subjective pain meanings. Without active encouragement and/or validation of the patient's personal pain narrative it is hypothesised that the patient may conceal or fail to report pain experiences or pain related consequences/concerns as he or she may not consider these to be the doctor's responsibility. In accepting the burden of daily pain and with limited expectations of the effectiveness and scope of available healthcare the patient may be indifferent about seeking advice or support.

### **12.2.2 Patients' Pain Meanings - the contribution of the findings to patient care**

The study findings support the literature which suggests that patients are not knowledgeable about RA, the disease (Hill et al, 1991; Minnock et al, 2003). Furthermore, it is found that patients have unmet educational needs regarding:

- strategies that can be used in the self-management of pain;
- knowledge of the consequences of chronic pain;
- knowledge of the mechanisms of pain in RA;
- knowledge of the actions, side effects, types and different ways to use analgesics;
- knowledge of rheumatologists' role and responsibilities;
- knowledge of the importance of the patients' contribution and role at the consultation.

The growing body of knowledge in the fields of RA self-management and chronic pain management supports involving the patient with RA in self-management and educational programmes which can have a positive effect on outcomes like pain (Barlow et al, 2000; Lorig and Holman, 1993; Niedermann et al, 2004; Riemsma et al,

2003; Robbins et al, 2001). The unmet educational needs of the patients involved in this study suggest that it is not yet valid to assume that patients are sufficiently well equipped to optimally manage pain.

The findings of this study support suggestions in the literature that patients with RA do not like to 'burden' others through talking about their concerns or difficulties (Bury, 1988; Williams and Wood, 1988) and build upon this, suggesting that patients specifically identify reporting pain to the doctor as potentially threatening to future patient-doctor relations. Given these findings, in addition to the proposed nondisclosure of pain consequences or experiences, which the patient has evaluated as being non-disease related, it is suggested that the health professional must actively encourage and validate the patient's pain narrative. The detailed findings from this study related to patients' pain-associated fears, concerns and support needs, at different stages of illness, may help the health professional to know something of what the patient may be experiencing, thus allowing them to engage more effectively with that patient (Carroll and Platt, 1998; Peters et al, 1998). Patient sub-groups identified as being at particular risk of suffering with pain (as identified from the study findings) include: those who are relatively young at the time of diagnosis, those experiencing an acute 'flare' (who may perceive that they cannot easily nor speedily access help), and those who are in the later stages of the illness (when it is perceived that the options for treatment are near exhausted).

A significant number of patients who attend rheumatology clinics are illiterate (Gordon et al, 2001a) and are not captured in the study sample. It is not known whether the pain needs of this group would differ from those sampled here. However, it has been found that those who are less well educated report higher pain intensity (van Lankveld et al, 1993; Young et al, 2000) and those who are more socio-economically deprived have worse outcomes in RA (Hamilton et al, 2001; McEntegart et al, 1997). Together these findings support further study of this patient group.

The findings of this study support and further develop what is already known about the important influence of health professionals in shaping patients' views about disease, illness and interventions (Brown, 1995; Skelton, 1998). The rheumatologists were identified as key information providers and notably it is suggested that information that doctors may fail to provide (e.g. information about analgesics) may also shape patients' impression of the relative unimportance of the omitted issues. Patients' beliefs about pain progressing as a consequence of ageing (in addition to RA progression) and concerns about the adverse effects of analgesics are

reflective of lay beliefs within western societies (Brouwer et al, 2005; Horne, 1997, p159-163) and were not always aligned with current medical thinking. Careful exploration of patients' views on such topics may reveal a relevant target for the supply of appropriate information and advice.

## **12.3 PAIN MEANINGS IN RA: RHEUMATOLOGISTS' PERSPECTIVES**

### **12.3.1 Advancing the Body of Knowledge about Rheumatologists' Pain**

#### **Meanings**

Studies investigating health professionals' understanding of chronic pain have tended to use simple questionnaires or vignettes (Cherkin et al, 1985; Tait and Chibnall, 1997), have commonly been focussed in the area of non-defined pain or cancer pain and were conducted in the United States (Green et al, 2003; Levin et al, 1998; Rainville et al, 1995; Wilson et al, 1992). Only two studies were identified which employed qualitative methodologies and presented a detailed account of how pain specialists made sense of chronic pain (Baszanger, 1992; Vrancken, 1989). There were no studies found exploring rheumatologists' views on pain, hence the findings from this study are novel, as well as relevant to patient care as these specialists primarily manage patients with pain.

The methodological approach to interviewing the rheumatologists built upon evidence from the literature that information gathered from experts regarding their knowledge and/or understanding does not always equate with the type of reasoning or information that they use to account for their actual clinical practice (Baszanger, 1992; Vrancken, 1989). Hence, the rheumatologists were asked to give examples from their clinical experience to illuminate their pain accounts and were asked to describe what they did in practice and why.

The findings from the study gave support to the suggestion in the literature that doctors are aware of the negative impact of chronic pain on the individual's sense of self (Paulson et al, 1999). Similarly, there was support for the generally held view, in this newly developing field of research, that doctors' medical training is a significant 'shaper' of how they think about pain (Rainville et al, 1995). Related to this medical background, rheumatologists' primarily associated pain in RA with patho-physiological changes within the body i.e. the pain

was fundamentally disease related. The biomedical explanations given were consistent and clear. In contrast, ideas about how social, psychological, personal, situational and/or cultural factors might moderate pain were more varied between the participants and the explanations lacked coherence in terms of providing underpinning theories. This latter finding is novel and challenges the view that doctors normally have systems for explaining illness features based upon strongly shaped scientific logic (Kleinman, 1980). The case examples that the rheumatologists presented to illustrate these accounts clearly indicated the significance of their clinical experiences in shaping their views about the complexity of pain.

Related to the issue of the perceived complexity of pain, and relevant to patient care, was the finding that rheumatologists presented the task of clinical pain assessment as being difficult and challenging. This important task appeared to be confounded by several factors - the lack of a coherent model or framework for clinical pain assessment, the limited time available for a consultation and the necessity to prioritise 'medical-type' tasks before pain assessment issues (a reflection of their perceived primary responsibility as the expert 'disease-manager'). From analysis of interviews and concurring with rheumatologists' direct statements on this issue, patients with RA do not have their pain adequately assessed at the rheumatology clinic. This point has been alluded to in only a few articles to date (Bellamy and Bradley, 1996; Wolfe and Pincus, 1999) and, until this point in time, has not been the subject of any detailed inquiry.

Inter-related with the finding that clinical pain assessment in RA is less than comprehensive, an additional barrier to pain management becoming a key goal in RA is the lack of available resources which would be required to provide comprehensive interventions and/or support. Studies in the field of clinical pain management have identified organisational and resource constraints as key factors circumscribing care but this has not been raised as an issue in RA management (Brockopp et al, 1998; Chapman et al, 2001). This study's findings highlight the complexity of the work of clinical pain management, the constraints upon best practice and rheumatologists' apparent frustration when they are knowingly compromising their 'ideals' of patient-centred care.



### **12.3.2 Rheumatologists' Pain Meanings - the contribution of the findings to patient care**

The findings of this study suggest that rheumatologists, as the gate-keepers of patient care, require more support and resources e.g. time, as well as restructured organisational systems and pain education to assist them in dealing with patients' pain. However, it is suggested that, at this stage, the findings be presented as *questions* that have been developed through this in-depth study of a previously unexplored area. These findings are an important first step towards further study and can be revisited for what they may hold in terms of providing explanation, support and/or refutation of subsequent research findings.

Nisell (2002) suggested that optimal management of pain may not be offered at the rheumatology clinic proposing that organisational and resource limitations may negatively impact upon attempts to approach pain comprehensively. The findings of this study suggest that Nisell's (2002) concerns were well founded. On a positive note, the findings of this study, albeit indirectly, support the recent initiatives of rheumatology nurse consultants developing nurse-led chronic pain management clinics within rheumatology departments to support patients who require individualised, non-medical management (Ryan, 2004).

## **12.4 THE PAIN OF RA: THE DIFFERENT PERSPECTIVES OF PATIENT AND RHEUMATOLOGIST**

One of the reasons for exploring the pain meanings of both patient and rheumatologist is that this type of knowledge has bearing on how effectively patients and doctors communicate about pain. Patient-centred care is advocated as the most appropriate approach to managing patients with chronic illness and is based upon effective communication and consideration of the personal meanings of illness for the patient (Mead and Bower, 2000). When patients and doctors have different views about disease or treatments this has a detrimental effect upon patient-doctor interactions and relations (Tuckett et al, 1985b; Walker et al, 1999). Few studies have compared patient and health professional views on pain and these have tended to focus on pain intensity alone (Mäntyselkä et al, 2001; Rutledge and Donaldson, 1998). From the literature it would appear that there have been no previous comparative studies of patient-rheumatologist pain meanings in RA.

### 12.4.1 Concordant and Divergent Views on Pain

The finding that both patients and rheumatologists primarily attributed pain to disease processes and gave biomedical explanations for pain was not unexpected and supports extant literature confirming the strength of influence of medicine and scientific knowledge in shaping western society's pain meanings (Morris, 1991; Rey, 1993). Further concordance was found between pain meanings constructed from the patient and rheumatologist interviews related to accounts of the consequences of pain. For both groups these accounts extended outwith the boundaries of the sensory and physical consequences of pain to incorporate the concept of 'threatened self'. This novel finding suggests that doctors are in a good position to empathise with patients and relate to their stories of suffering, an approach associated with patient satisfaction and with an increased sense of control in living with RA (Carr et al, 2003; Coyle, 1999; Ryan et al, 2003b).

There were two patient-generated themes related to suffering which were not evident in rheumatologists' accounts i.e. suffering during acute flares and suffering during the late stages of illness. This finding may be the result of the shorter and more focused interviews for the rheumatologists or may reflect a sub-sample of patients whose suffering is overlooked; this area requires further exploration.

Patient and doctor views appeared to diverge in relation to issues of responsibility for pain and evaluation of the legitimacy of pain. In essence, patients viewed doctors to be responsible for the management of pain that was disease related i.e. physical or 'legitimate' pain, and assumed self-responsibility to manage an array of social, psychological and emotional consequences of pain. In contrast, the doctors' accounts suggested that, 'ideally', their responsibilities more closely reflected a comprehensive biopsychosocial approach where all pain and pain related distress was deemed legitimate. The differences noted could be explained with reference to traditional lay views of medical care (Gamsa, 1994) and rheumatologists' knowledge of patient-centred approach to care (Ferrari, 2000). However, more detailed analysis suggested that in the *clinical* context, the rheumatologist assumes 'operational' type pain meanings which are more closely aligned with the patients' pain meanings, which may enable the clinic to function but at the cost of sidelining patients' personal pain meanings.

Exploration of how patients and rheumatologists situate their pain-talk regarding medical care and clinical interactions is a novel area of research with respect to RA and one that is pertinent to practice given that meanings vary in relation to context (Cassell, 1982). The study findings suggest that in the clinical context both patient and doctor may unwittingly negotiate and co-create pain meanings which conform to the dominant biomedical discourse of pain despite both having more complex and sophisticated understanding of the pain phenomenon. Patients and doctors would appear to be reduced to simple biomedical, dualistic thinking in the clinical context. Patients appear to be influenced strongly by their experiences at the clinic and doctors' pain meanings appear to be shaped (and constrained) by their perception that there are limited resources and organisational barriers to pain management in rheumatology. If the rheumatologist does adopt a biomedical approach to pain at the clinic, then he or she is likely to reinforce patients' conceptions of the medically focused role of the doctor, subsequently shaping patients' expectations and pain presentations. In this way, it may be said that the dominance of the biomedical discourse of pain at the clinic self-perpetuates.

Hypothetically, these clinical-contextual pain meanings may serve an important function in allowing the rheumatologist to focus on the prioritised medical issues (hence honouring his or her primary responsibilities) whilst avoiding tackling the complex, non-disease related pain issues which, it is perceived, cannot be managed effectively given the limited time and resources available within the 'cure' oriented hospital system (Rich, 2003). The problem with this scenario is that it stifles patients' subjective pain meanings and conspires against notions of patient-centred care and may contribute to the under-assessment and under-treatment of pain and explain patients' continued rating of pain as a priority for treatment in RA (Heiberg and Kvien, 2002; Minnock et al, 2003). The development of these ideas from the study findings may serve as a point of departure for future studies which should endeavour to explore more directly the interactions taking place at the clinic and the pain meanings constructed by patient and doctor.

#### 12.4.2 Comparing Patient and Rheumatologist Pain Meanings - the contribution of the findings to patient care

The clinical relevance of the findings from the comparative study of patient and doctor pain meanings can be viewed on two levels, as follows:

- Specific pain-relevant topics/issues which appeared mismatched in the patient and doctor accounts; and
- The wider issue of the *concordant* patient/rheumatologist clinical pain meanings, which have a biomedical focus, and the factors which appear to support this.

From the study findings it is suggested that rheumatologists and other health professionals involved in the care of those with RA pay particular attention to assessing the needs of those who are in the late stages of illness. Health professionals should consider investigating the needs of patients experiencing acute 'flares' along with evaluation of how easily and quickly these patients can access specialist services. It was found that patients are not as knowledgeable about the effects and uses of analgesics as rheumatologists think they are. Therefore, it is suggested that health professionals make careful assessment of the patient's beliefs and concerns about analgesic medications and their use; addressing these, where appropriate, with individualised advice and information.

This study has highlighted the issue that in the clinical context both patients and rheumatologists 'work' with a biomedical frame of reference regarding pain, which conspires against a patient-centred model of care. Having illuminated this issue, the findings also suggest which factors or conditions appear to support this phenomenon. These factors and/or conditions include:

- Multiple patient barriers to reporting pain in RA;
- Organisational barriers;
- Limited resources, e.g. time, staff, interventions;
- Patients' and rheumatologists' inadequate knowledge and understanding of chronic pain and its management.

This study's findings do not extend to specifically outlining how these factors and/or conditions should be managed to assist the movement towards care where *patient* pain meanings are comprehensively explored and

addressed. However, the findings, albeit indirectly, provide support for particular initiatives and standards of care for RA management. In Figure 12.4.2 standards of care and practice initiatives in RA management have been adapted from the standards of care document for people with inflammatory arthritis (ARMA, 2004) to emphasise the specific focus that is needed on pain in RA.

**Figure 12.4.2 Standards of Care and Practice Initiatives in RA which are, indirectly, supported by the Study's Findings (standards and initiatives adapted from ARMA, 2004)**

The study findings, indirectly, support the following standards of care:

- Patients need advice on the self-management of pain;
- Patients need advice on when and how to seek advice for pain and the consequences of pain;
- Patients need individualised care to address their specific pain problems in RA;
- Patients should be offered self-management training which incorporates pain management principles provided by a multi-disciplinary team in either the primary or secondary care setting;
- Patients should be made aware of the national and local voluntary organisations which provide arthritis and/or pain self-management training and support.

The study findings, indirectly, support the following practice initiatives in RA management:

- The development of nurse-led helplines to provide patients with advice and rapid access to rheumatology services when required;
- The development of nurse and/or allied health professional led clinics and/or services which can provide individualised pain management and support.

## **12.5 SUGGESTIONS FOR FUTURE RESEARCH**

### **12.5.1 Investigating Patient Barriers to Reporting Pain**

Patients' pain meanings suggest that there are multiple barriers to effective and comprehensive pain management in RA. This study identifies several patient-related issues which may contribute to patients' non-report of pain at the clinic. These issues can be listed as follows: resignation to expect pain in RA, concern about the adverse effects of medications, concern about the impact of pain-reporting on future patient-doctor relations and a belief that the primary aim of treatment is to manage the disease (and not pain). Similar issues have been documented

for patients with cancer and led to the development of the Barriers Questionnaire (BQ; Ward et al, 1993), subsequently modified to the BQ II (Gunnarsdottir et al, 2002). This self report questionnaire is a valid and reliable measure for pain-related barriers to cancer pain management and includes factors such as, concerns about side-effects of analgesics, fatalistic beliefs about pain in cancer and the view that 'good' patients do not complain about pain (Gunnarsdottir et al, 2002). Similar types of patient attitudes and beliefs have been reported for patients with AIDS and, as in the studies of patients with cancer, such views are associated with the under-treatment of pain (Breitbart, 1998). The Barriers Questionnaire framework could be used as a platform for the development of a RA-specific questionnaire, incorporating additional dimensions found in this study e.g. patients identifying psychological and social pain-related concerns as their own responsibility and beliefs about pain being best assessed via clinical tests/measures.

The specific study of patients' beliefs regarding analgesics and their use is warranted in its own right as an area where there was strong suggestion that patients' 'false' beliefs about the adverse effects of analgesics are linked to less than effective use of these medications. Given that analgesics are commonly prescribed in RA lends weight to the argument for further study in this area. To build upon this study's qualitative findings an appropriate first stage would be to determine the extent of these beliefs using a larger sample size and investigate whether there are any relations between these and patients' reports of analgesic consumption and their pain experience. This type of investigation could make use of existing questionnaires, for example, the Beliefs about Medicines Questionnaire (Horne et al, 1998 in Horne and Weinman, 1999), the Pain Medications Attitude Questionnaire (Hoskins et al, 2002) or examine the possibility of modifying the Barriers Questionnaire (Ward et al, 1993). This type of study would ideally precede an investigation into the effects of providing specific education and/or addressing patient concerns about analgesics to determine whether this would alter analgesic usage and pain related outcomes.

From the patient findings it is suggested that the 'audience', or *who* the listener is, will influence *what* the patient says about pain. For example, the patient may consider it more appropriate to discuss their concerns about pain and altered mood with the rheumatology nurse than with the rheumatologist. Kotarba (1983, p17) refers to 'situational secrecy' to describe the phenomenon where pain reporting appears dependent upon several factors, those being, the patient, the context and the audience. An observational study, collecting information about who

says what and to whom in different settings, with regard to pain, may be a first step towards identifying how patients might be best supported to relay the pain accounts which are important to them.

## **12.5.2 Exploring Patient Perspectives on Arthritis Self-Management**

### **Programmes**

A significant proportion of the patients sampled (45%) stated that they had not, and would not, consider attending patient led self-help groups or educational sessions organised by an arthritis associated organisation e.g. Arthritis Care. However, these same patients indicated that they would consider attending a hospital developed and delivered educational program. This topic was not explored in-depth, as the study's focus had to remain on pain, however, these findings raise important questions about patient perceived barriers to attending arthritis associated courses. This would be an area worthy of investigation as the Arthritis Self-Management Programme (ASMP, organised by Arthritis Care) has been found to significantly reduce patients' pain and improve health status (Barlow et al, 2000). In addition, these types of programmes would appear to be more widely available to patients than hospital based schemes which, from the findings of this study (and supported by the literature) would appear to be in short supply (Gray and Muirie, 2002).

## **12.5.3 An Integrated Study of Factors Shaping Pain Meanings – an ethnographic approach**

The most comprehensive way to further explore the interaction between individuals' pain meanings and the clinical context would be to conduct an ethnographic study at a variety of hospital sites. In this way patients' and doctors' pain meanings could be further explored in parallel with observation of their respective actions at consultations. In addition to this, findings related to the organisation and resources specific to the study site could be integrated into the inquiry. Accessing rheumatology units in different countries, where care varies from the UK, may provide a useful source of comparative sites for studies. This type of on-site approach would also enable access to other important members of the healthcare team, as well as to medical staff at different stages of training. Ideally future studies would incorporate exploration of patients' experiences at these different sites along with assessment of whether there is evidence to suggest that comprehensive assessment and management of pain in RA positively influences pain related outcomes and/or quality of life for patients. Longitudinal,

observational study of patients' interactions with health professionals, from the time of diagnosis onwards, would enable the additional exploration of the nature and extent to which healthcare professionals influence patients' pain meanings e.g. expectations of pain, ideas about pain control etc.

#### **12.5.4 Extending Inquiry into the Different Perspectives of Patient and Doctor Regarding Pain**

To determine the extent of the pain meanings described would require the use of a methodology that would enable greater numbers to be involved and provide an opportunity for equitable presentation of diverse pain meanings to both patients and doctors, enabling direct comparison of their selected responses. The use of Q-methodology would facilitate such a study (Corr, 2001; Stainton Rogers, 1991). The findings from the current study provide a rich source of views about pain in RA that could be used as the starting point for the formation of a collective pool of pain-statements for a Q-methodology study. This would allow the inquiry to be extended to include patients who have concurrent, painful conditions and those who choose not to attend the rheumatologist (two patient groups which were excluded from this study). The pain perspectives of greater numbers of rheumatologists, including those with different levels of experience could be examined as well as the views of those working in non-NHS, private clinics to further understanding about the possible influence of organisational and contextual barriers to pain management.

One of the principal shapers of pain meanings in RA, for patients and doctors, was the strength of their pain attributions to a progressive disease, which was viewed as not fully controllable. In all accounts there was an indication that pain was expected, along with a primary focus on the importance of disease-modifying interventions and emphasis on the limited effectiveness of the interventions available. All of these factors appeared to assist in displacing the importance of pain management i.e. relative to RA pathology - pain was not acknowledged as being especially harmful in its own right. It can be hypothesised that similar interpretive frameworks may be relevant for other groups of patients with chronically painful incurable conditions e.g. osteoarthritis, lupus, osteoporosis etc. who are similarly managed by healthcare professionals working within NHS hospitals. As each illness has its own identity (Moss-Morris et al, 2002) this study's findings cannot automatically be generalised to other conditions. However, the findings of this study raise questions about the



extent to which pain management goals are displaced by a focus upon disease control or cure, with a concurrent (and resultant) undisclosed patient suffering and unrecognised need for greater, patient-focused care.

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